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An Analysis of Adherence & Equity in Access to TB services in Mitchell's Plain, South Africa

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DCRSUM001**

**A mini dissertation presented for the Degree of Masters in Public Health
(Health Economics) in the Department of Public Health and Family Medicine,
University of Cape Town**

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DECLARATION

I declare that this thesis is my original work and has not been submitted for any academic or examination purpose at any other university. All the relevant sources of knowledge that I have used during the course of writing this dissertation have been cited/referenced.

Sumaiyah Docrat

30.10.2012

Date

DEDICATION

To my parents, my sisters, and to all of the wonderful friends, near and far, who
continue to bring light into my life.

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I would like to extend special gratitude to my supervisor, Susan Cleary for her guidance, support and unwavering encouragement.

I am grateful to the REACH (Researching Equity in Access to Health Care) research team, particularly those who contributed to the methods development, data collection and study conceptualization and to the patients and health workers who agreed to be involved in the REACH project.

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ABSTRACT

Objectives: The control of tuberculosis (TB) in South Africa has fallen short of the targets outlined by the World Health Organization and without improvement; TB is expected to have grave consequences for both the mortality and morbidity of South Africans as well as crippling financial consequences for the public health system. While services in the public sector are free at the point of use, little is known about overall access barriers and their implications for treatment adherence. This paper explores these barriers from the perspective of TB patients enrolled in Directly Observed Treatment, Short-Course (DOTS) in Mitchell's Plain, South Africa.

Methods: Using a comprehensive framework of access, in-depth interviews were conducted with 334 TB-patients across five facilities in Mitchell's Plain, to assess barriers across the dimensions of availability, affordability and acceptability. Summary statistics were computed and comparisons of access barriers between adherent and non-adherent groups, and between socioeconomic groups were explored using bivariate, multivariate linear and logistic regressions.

Results: Among the respondents, 244 (73.05%) met the criteria for adherence (i.e. reported that they had never missed a dose of TB medication) while 90 (26.95%) met the criteria for non-adherence. Marital status, age, birth province, costs of self-care and costs of other providers were found to be significantly associated with adherence (P -values < 0.05). There was no significant evidence of inequalities in access by socioeconomic status (all P -values > 0.05). Nonetheless, the results revealed that the poor face increased costs of accessing TB-services, compared to the rich, though this association was not deemed to be significant.

Conclusions: Our findings indicate that non-adherence is not associated with access barriers and there is therefore no evidence of inequity in adherence to DOTS TB- treatment. In addition, our findings show that there is no significant evidence of inequalities in access to DOTS TB-services in Mitchell's Plain, by socioeconomic status. This study discovered that there is a need to explore the high costs of using TB-services, specifically high transport costs which are associated with the frequency of clinic visits.

LIST OF ABBREVIATIONS

WHO	World Health Organization
TB	Tuberculosis
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome
MRC	Medical Research Council
DOT	Directly Observed Treatment
DOTS	Directly Observed Treatment-Short Course
ILO	International Labour Organization
GCI	Global Competitiveness Index
HDI	Human Development Index
GDI	Gross Domestic Income
ART	Antiretroviral Therapy
ANC	African National Congress
DALYs	Disability-Adjusted Life Years
MDGs	Millennium Development Goals
IMR	Infant Mortality Rate
AMR	Adult Mortality Rate
PPIs	Public-Private Interactions
CUBP	Clinic Upgrading and Building Program
NTCP	National Tuberculosis Control Program
MDR-TB	Multi-Drug Resistant Tuberculosis
XDR-TB	Extremely Drug Resistant Tuberculosis
IUATLD	International Union Against Tuberculosis and Lung Diseases
LMICs	Low and Middle Income Countries
OOP	Out-Of-Pocket payments
REACH	Researching Equity in Access to Healthcare
IDRC	International Development Research Centre
MCA	Multiple Correspondence Analysis
PCA	Principal Component Analysis
PHC	Primary Health Care
CHC	Community Health Centres
CNP	Clinical Nurse Practitioners
SES	Socioeconomic Status

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PART A: RESEARCH PROTOCOL

INTRODUCTION

Tuberculosis (TB) represents one of the most pressing global health issues and one of the greatest challenges to the health of South Africans (WHO 2011a). Despite the adoption of the Directly Observed Treatment, Short-Course (DOTS) strategy in 1996 and significant investments in TB control, the case detection rate remains far below the targets outlined by the WHO and without improvement, TB is expected to have grave consequences for both the mortality and morbidity of South Africans as well as crippling financial consequences for the public health system (Mukinda et al. 2012). The burden of non-adherence to curative TB treatment has been widely acknowledged as being a key constraint to the global control of TB. Where non-adherence is the result of unfair, unjust, avoidable or unnecessary forces, equity concerns intensify its importance. TB services in the South African public sector are free at the point of use, however, little is known about overall access barriers and their implications for treatment adherence. This paper explores these barriers from the perspective of TB patients enrolled in Directly Observed Treatment, Short-Course (DOTS) in Mitchell's Plain, South Africa. The following chapter introduces the reader to the methodological approach to the study. It presents the research design, describes the study area and population, the data sources and research instruments as well as the methods employed in data analysis. Further, this chapter includes discussions of the requisite ethical considerations to ensure its compliance with the appropriate regulatory research governing bodies.

BACKGROUND

Introduction

There exists widespread agreement that the health of individuals is a primary determinant of living a prosperous life; good health has been associated with increased enrolment and success in school, protection from financial vulnerability, productivity in labour, increased life security as well as growth and economic development of nations globally (Department for International Department 2006). As highlighted by Nobel Prize winner Amartya Sen (2002, p. 660), "Health is among the most important conditions of human life and a critically significant constituent of human capabilities which we have

reason to value" (Sen 2002; O'Donnell et al. 2008). In recognition of the importance of good health and its positive gains, numerous international human rights treaties and national constitutions have recognized health (and access to health services) as an inalienable right – one that all individuals should be increasingly able to realize. Nonetheless, there exists undisputed evidence that the health of individuals within and across nations varies significantly as a result of socio-economic disadvantage and geographic location (Whitehead 1992; Mackenbach & Kunst 1997). Adequate access to health services, one vehicle through which individuals can improve their health, has persisted as an increasingly serious global concern whereby approximately 1.3 billion people, worldwide, remain unable to access health care as a result of largely avoidable financial, physical and cultural barriers (ILO & WHO 2006; Thiede et al. 2007).

Equity as a Global Concern

Equity has endured as one of the most highly-debated concepts in the global health policy landscape (McIntyre 2007). The early twenty-first century has seen a continuation of the increasing inequalities which exist in health outcomes across nations, communities and geographical regions (Ong et al. 2009; Leon & Walt 2001). The need to address equity in health was originally provided by the relevant articles of the World Health Organization's Alma Ata Declaration in 1978 which promoted the need to improve the health profiles of those most in need through primary health care and preventative programs (Ong et al. 2009). In 1986, the World Health Organization (WHO) defined equity in health as a situation in which "everyone should have a fair opportunity to attain their full health potential and...that no one should be disadvantaged from achieving this potential, if it can be avoided" (Whitehead 1992a, p. 7)

What seems most consistent from all literature is the notion that a health inequity exists if health inequalities are considered to be: (1) unfair; (2) unjust; (3) avoidable and; (4) unnecessary; and further, that tagging a difference in the health profile of one group as inequitable involves a moral and ethical judgment of the fairness of the causes of the inequalities (Whitehead 1992; Krasnik 1996; Braveman & Gruskin 2003). Health differentials are considered inequitable largely based on whether an individual's health status is as a result of circumstances out of their direct control; general consensus among scholars has broadly grouped health differentials determined by the following circumstances as inequitable:

1. Health-damaging behaviour where the degree of choice of lifestyles is severely restricted.

2. Exposure to unhealthy, stressful living and working conditions.
3. Inadequate access to essential health and other public services.
4. Natural selection or health-related social mobility involving the tendency for sick people to move down the social scale.

(Whitehead 1992)

The very nature of the health inequalities which exist in the world today illustrates the importance of equity in health as a global concern. Health differentials are pervasive and often (though not exclusively) affect those that are already disadvantaged the most (Ong et al. 2009). There exist weaker chances of survival, higher premature mortality rates, increased burdens and earlier onset of both chronic and communicable disease as well as increased disability among certain groups, in all regions of the world, across all political and social systems (Whitehead 1992; Mackenbach & Kunst 1997). Higher rates of mortality and morbidity are noted among poorer populations relative to their better off counterparts, yet despite their increased needs, these groups use health services less and frequently contribute a greater share of their income to accessing treatment than those who are less-disadvantaged (O'Donnell et al. 2008). "Indeed, some non-poor households may be made poor precisely because of health shocks that necessitate out-of-pocket spending on health" (O'Donnell et al. 2008, p. 1).

What is made clear from all discussions on equity, particularly within the context of health and health services is the fact that it can only be achieved if there exists a fair opportunity for all to achieve health. This understanding reflects the central role of access; if health services are the vehicle through which populations and individuals can improve their health, then it undoubtedly follows that equity in health is dependent on the equity which exists in access to health services (Krasnik 1996; Whitehead 1992). A central principle for action towards achieving equity in health has therefore become targeted at ensuring high quality health care is accessible to all (Whitehead 1992). With this in mind, health policies are being focused on ways to enhance access among disadvantaged groups through: (a) resource allocation mechanisms and the geographical distribution of health services being based on social and health needs; (b) prioritizing the need to understand the experiences of access to health services by all social groups to explain and address reasons for poor use of essential services and; (c) examining the quality of care and cultural factors which influence access (Whitehead 1992).

Despite the commitment to equity in health reflected by (and since) the World Health Organization's Alma Ata Declaration in 1978 and the growth of primary health care initiatives worldwide, health inequities have persisted where the poor continue to lack access to quality health services. Wealthier nations have been able to adopt pro-equity policies with a greater level of ease whereas progress within poorer nations has been hampered by the emergence and rapid growth of HIV/AIDS and other communicable diseases, human resource shortages as a result of globalization as well as poor management, stewardship and monitoring which disable health policies from being successfully implemented (McIntyre, Thiede, et al. 2006; Chetty 2007; Coovadia et al. 2009). Macro-economic policies have also stalled health sector reforms to address health inequity particularly in low and middle income countries where neo-liberal reforms have imposed highly regressive health financing schemes on disadvantaged groups (Mackenbach & Kunst 1997; McIntyre 2007; Gilson et al. 2007).

Since the 1980s, health equity has moved from being considered 'ideologically unacceptable' to the top of the health agendas of policy makers, donors, nongovernmental organizations, governments and international organizations across the globe (O'Donnell et al. 2008). The pursuit of equity in health and health service access remains an overarching goal for health systems particularly in recent years with the emergence of interest in universal health coverage and the need to provide broad-based, context-specific primary health care (Ong et al. 2009). Hope lies in the potential of strategically designed and effectively managed health systems that are able to deal with health inequity by addressing the specific circumstances of marginalized populations and the physical, financial and cultural barriers they face in accessing health care (Gilson et al. 2007). Equitable health systems have the capacity to "generate wider benefits: a sense of life security, well-being, social cohesion and confident expectation of care in times of illness" (Gilson et al. 2007, p. 14).

The Global TB Landscape

Tuberculosis (TB) represents one of the most pressing global health issues and since 1993, has been considered a public health emergency (WHO 2011a). TB is spread between individuals by airborne droplet particles containing mycobacterium tuberculosis bacilli. This can occur when an individual with tuberculosis coughs or sneezes, expelling particles containing mycobacterium tuberculosis bacilli which are then inhaled by another individual and passed into the lungs where replication occurs. According to the WHO (2011), TB is a worldwide pandemic whereby low and middle income countries carry 90% of the worldwide burden; Africa assumes 26% of cases of TB, while 59% of all new cases are emerging from

Asian countries (WHO 2010b; WHO 2011a; Lawn & Zumla 2011). The past two decades have seen an escalation in TB morbidity whereby prevalence estimates in 1993 of 7-8 million cases have grown to 8.5-9.2 million cases in 2010- more than at any other time in history (WHO 2011a). TB is accountable for the most deaths from an infectious disease worldwide, after HIV/AIDS, with estimates reaching 1.2–1.5 million deaths in 2010 (WHO 2011a). Incidence rates of TB have declined marginally at a rate of almost 1% per year since 2002; however, the absolute burden continues to increase worldwide (Lawn & Zumla 2011; WHO 2011a). According to the WHO (2011), there continues to be a cloud of ambiguity surrounding estimates of TB prevalence and incidence due to poor surveillance systems which fail to capture all TB cases (WHO 2011a). There are a significant number of individuals who do not seek treatment, are not diagnosed or whose diagnoses go unreported to the appropriate authorities and as such, estimates may be even greater than reflected in most published reports (WHO 2011a).

Since the acceptance of TB as a worldwide emergency in 1993, the Directly Observed Treatment, Short - Course (DOTS) strategy has been the main mechanism by which the WHO's Stop TB Campaign and the Global Plan to Stop TB aim to guide national TB policy to reach the Millennium Development Goal of "reduc[ing], by 2015, the prevalence of and deaths due to TB by 50% relative to 1990 and revers[ing] the trend in incidence" (WHO 2010b, paragraph 1). Treatment of active tuberculosis is done with a standardized range of anti TB drugs, which must be monitored in order to ensure that individuals take and complete their course of medication. The DOTS strategy is based on five key covenants: (1) a sustained government commitment to prioritize TB control; (2) the diagnosis of TB through sputum microscopy; (3) standardized and supervised treatment in a supportive environment; (4) uninterrupted drug supply and; (5) regular monitoring of patients and health systems (Western Cape Department of Health 2004; Raviglione & Uplekar 2006). In 2006, these guidelines were reassessed to address emerging challenges involved in TB control and a provocative target was set to eliminate TB as a public health problem by 2050 (Lawn & Zumla 2011; WHO 2011a). TB treatment remains one of the most cost-effective treatment regimens for disease and when administered appropriately is able to cure patients and prevent transmission (Lönnroth et al. 2010). Furthermore, evidence has shown that timely treatment has the capacity to produce economic benefits which can amount to ten times the investment (Lönnroth et al. 2010)

The successes of the DOTS strategy cannot go unnoticed. Between 1995 and 2010, 55 million TB patients have been treated under DOTS, curing 46 million cases and saving approximately 6.8 million

lives (WHO, 2011; Glaziou et al, 2011). Nonetheless, current forecasts of TB incidence, and its marginal decline of 1% per year, have suggested that the target of halving TB prevalence by 2015 and eliminating TB as a public health crisis by 2050, will not be met (Lawn & Zumla 2011; WHO 2011a). The case detection rate (CDR) for TB ("an approximate indication of the proportion of all incident TB cases that are actually diagnosed, reported, and started on treatment" (WHO 2011a, p. 29)) has stabilized at 60%, falling far below the 70% target outlined by the Millennium Development Goals (WHO 2011a; Lawn & Zumla 2011). Furthermore, incidence projections have illustrated that "even if the Global Plan to Stop TB were successfully implemented, incidence would only decrease at around 6% yearly, meaning that worldwide incidence rates in 2050 would remain 100-times higher than the elimination target" (Lawn & Zumla 2011, p. 68).

The challenges of controlling the TB pandemic can broadly be summarized into six categories: (1) the HIV-associated TB epidemic; (2) the escalating problem of drug-resistant TB; (3) weak health systems which fail to address the key socio-economic factors which determine general population health; (4) a lack of resources; (5) a failure of TB preventative interventions to have been implemented at scale and; (6) long treatment delays (Lönnroth et al. 2010; Lawn & Zumla 2011).

The Research Context

Health care access and delivery is undoubtedly a global concern, however, central to any analysis and appreciation of health provisioning is an understanding of the unique environment in which health services are sought. The following discussions provide the reader with the context in which access to TB services and the mechanisms of ensuring such access are being studied. In particular, a summary of the organization of the South African health sector is provided as well as the primary health challenges currently being faced by the country. This will lay the foundation for crystallizing the research problem later on in the chapter.

South Africa: General Overview

Since the democratization of South Africa in 1994, the government has made significant progress in reversing the effects of the apartheid legacy which was characterized by severe inequality, health and development policy which was disproportionately focused on ensuring the survival of the white population's rule, as well as a fragmented, highly segregated and largely privatized health sector

(McIntyre, Thiede, et al. 2006; Chetty 2007; Coovadia et al. 2009). Today, South Africa is home to approximately 50.59 million people and represents a multiracial democracy comprised of a 79.5% black African majority, and minority groups of a 9.0% White population, 9.0% Coloured population and a 2.5% Indian population (Coovadia et al. 2009; StatsSA 2011)*. It has been estimated that 61% of South Africans reside in urban areas and 39% live in rural areas (World Bank 2011).

With regards to development, South Africa has seen modest, positive economic growth since the first democratic elections in 1994 with annual growth rates falling between 2% and over 5% over the past decade (Coovadia et al. 2009). In 2011, South Africa's Gross Domestic Income (GDI) Per Capita in PPP[†] terms was estimated at US\$ 10,278 (Adelzadeh & UNDP 2003) and the nation has earned a Global Competitive Index[‡] (GCI) score of 4.34 placing it in the 50th position of 142 countries which confirms its place among the most emerging competitive economies (World Economic Forum 2011). However, despite its positive economic performance, South Africa is still ranked in the company of the poorest nations in the world by its Human Development Index[§] (HDI) score - a summary composite index that measures a country's average achievements in three basic aspects of human development: life expectancy, education, and a decent standard of living (by GDI per capita (PPP US\$)) (UNDP 2011). The HDI for South Africa was 0.61 in 2011, falling from 0.72 in 1990 and placing it in 123rd place of 187 countries (Adelzadeh & UNDP 2003; UNDP 2011). This measure indicates that despite reasonable economic growth, and a concerted effort by the South African government, the living standards and experiences of societal life for the majority of South Africans has worsened over the past two decades (Adelzadeh & UNDP 2003).

* The terms allocated to racial groups are consistent with those used in the national census and do not accept racial attributes of any kind.

† GDI per capita in PPP terms (constant 2005 international \$): Aggregate income of an economy generated by its production and its ownership of factors of production, less the incomes paid for the use of factors of production owned by the rest of the world, converted to international dollars using purchasing power parity (PPP) rates, divided by midyear population (UNDP 2011)

‡ Global Competitiveness Index measures the set of institutions, policies, and factors that set the sustainable current and medium-term levels of economic prosperity; this measure indicates the level of prosperity that can be earned by an economy (World Economic Forum 2011)

§ The Human Development Index is a composite measure of human development which includes life expectancy, literacy, education and standards of living (UNDP 2011)

According to the World Health Organization, approximately 26.2% of South Africans live in absolute poverty^{**}, representing an estimated 13.3 million people (WHO 2011b). Recent estimates have suggested that 37% of the South African population is unemployed (Coovadia et al. 2009). In 1994, the newly elected government was committed to reversing the wealth disparities which were produced by years of racial discrimination; government policy became focused on improving access to basic social services by improved funding to these sectors particularly through a national system of social grants (Coovadia et al. 2009). Currently this system successfully serves approximately 12.4 million beneficiaries through disability, pension and child support grants (Coovadia et al. 2009). However, wealth disparities have persisted and worsened since 1994; the Gini-coefficient, a measure of income inequality (in a range from zero to 1, with zero referring to total equality), rose from 0.56 in 1995 to 0.78 in 2005 –one of the highest in the world (Coovadia et al. 2009). The average annual income among the poorest groups is R4,314 (about US\$516) compared with an average annual income of R405,646 (about US\$48,462) among the wealthiest groups (Coovadia et al. 2009).

Over the past two decades, the nature of the unequal income distribution has changed. As many of the rural poor migrate to the urban areas in search of improved employment prospects, the population of urban poor has risen by 4.7 million between 1993 and 2008 (May 2010). As such, South Africa has seen a rise in urban poverty and this has been reflected by an increase in urban income inequality and a reduction in rural income inequality (Adelzadeh & UNDP 2003). Racially, “there is a rising polarization of income within all racial groups...however, the deterioration of income equality is more severe among African, Coloured and Indian households than among White households” (Adelzadeh & UNDP 2003, p. xvi). Inter-race comparisons of HDIs in South Africa have also showed that despite a slight improvement from 1990, the HDI for the black African population in South Africa has continued to fall far below the HDI for the White population (Adelzadeh & UNDP 2003).

What is seemingly clear is that the gains in the national economy have failed to translate to the prosperity of the South African population. After 18 years, South Africa is still struggling with the “legacy of apartheid and the challenges of transforming institutions and promoting equity in development” (Coovadia et al. 2009, p. 817).

^{**} Population living below US\$1.25 PPP per day

South African Health Indicators

Despite its economic position as a middle-income country, the health of South Africans is worse than many of the poorest populations in the world particularly due to the effect of the concomitant epidemics currently being faced by the country (Coovadia et al. 2009). "Poverty related illnesses such as infectious diseases, maternal death, and malnutrition, remain widespread, and there is a growing burden of non-communicable diseases [furthermore;] HIV/AIDS accounts for 31% of the total disability-adjusted life years (DALYs)^{††} of the South African population, with violence and injuries constituting a further cause of premature deaths and disability" (Coovadia et al. 2009, p. 817).

South African health indicators illustrate the poor progress that has been made towards the achievement of the health-related Millennium Development Goals. Life expectancy in 2009 for males was 54 years and 55 years for females, having substantially decreased from 1990 when life expectancy was estimated to be 59 years for males and 68 years for females (WHO 2011b). Of particular concern, the Adult Mortality Rates (which provide the probability of dying between age 15 and 60 years) have increased by just over 52% for males and around 150% for females between 1990 and 2009 (WHO 2011b). The Infant Mortality Rate (IMR) in 2009 was 43/1000 live births showing a modest decrease from the 1990 IMR of 48/1000 live births however, 62 children per 1000 still die before their fifth birthday- a rate that has not improved since 1990 (WHO 2011b). In fact, the under five mortality rate for South Africa in the year 2000 had actually increased to 77 children per 1000; South Africa representing only one of twelve countries who saw child mortality increase since the Millennium Development Goals were established (WHO 2011b; Coovadia et al. 2009).

One of the greatest challenges to South African health has been the burden of communicable disease, particularly the concurrent HIV/AIDS and TB epidemics (Abdool-Karim et al. 2009). With only 0.7% of the world's population, South Africa carries approximately 17% of the global burden of HIV/AIDS, "and one of the world's worst tuberculosis epidemics, compounded by rising drug resistance and HIV co-infection" (Abdool-Karim et al. 2009, p. 921). In 2011, the prevalence of HIV/AIDS was 10.6%, representing just over 5.36 million people living with the disease, while the prevalence rate of TB

^{††} The disability-adjusted life year (DALY) is a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death.

reached 795 per 100 000 people – a rate that has nearly doubled over the past decade (Health Systems Trust 2012). With the development of drug resistant strains of TB, it has become increasingly evident that the South African health system cannot cope (Abdool-Karim et al. 2009). After a substantial period of denial and a lack of political interest which saw the unnecessary death of thousands of South Africans, the country has finally begun to see some successes in the control of both HIV/AIDS and TB whereby there has been a marked improvement in access to condoms as well as an expansion of tuberculosis control programs, and a modest scale-up of free antiretroviral therapy (ART) – the standard means of reducing morbidity and mortality among those infected with HIV/AIDS (Abdool-Karim et al. 2009; Coovadia et al. 2009).

Nonetheless, efforts to combat the co-epidemics of HIV/AIDS and TB have been hampered by failures in the implementation of policies and an inability to successfully integrate HIV/AIDS and TB services with each other and with the wider primary health care system (Abdool-Karim et al. 2009). Furthermore, the progression of disease has created a need for increasingly complex and expensive interventions which are persistently inaccessible to those who require them the most (Abdool-Karim et al. 2009). HIV/AIDS and TB continue to cause devastating mortality among South Africans. Although the full scale of HIV/AIDS-related mortality has been difficult to assess due to misclassification, to date, over 2.6 million South Africans have died due to HIV/AIDS, predominantly children under five and young adults (Harrison 2009). It is assumed that a considerable amount of deaths classified to be caused by non-communicable disease have in fact been HIV/AIDS-related and as such, the mortality rates are expected to be significantly higher than reflected in most published reports (Harrison 2009). According to the WHO (2011), cause-specific mortality rates have shown that HIV/AIDS kills 627 (511-775) per 100,000 people while TB causes death for 52 (29-85) per 100,000 HIV-negative people, in South Africa (WHO 2011b).

Chronic non-communicable diseases are also a major contributor to the burden of disease in South Africa and evidence has suggested that after communicable disease, the prevention of chronic conditions should be prioritized within the national health agenda (Puoane et al. 2008). Chronic non-communicable diseases encompass cardiovascular diseases, diabetes, certain cancers as well as chronic respiratory diseases (WHO 2011b). These conditions are steadily growing, affecting all population groups (WHO 2011b). Of the primary conditions which contribute to mortality in South Africa, four of the ten diseases belong to this category causing a loss of approximately 65 000 lives per year through: (1) ischemic heart disease (6.6% of total deaths); (2) stroke (6.5% of total deaths); (3) hypertensive

disease (3.2% of total deaths) and; (4) diabetes mellitus (2.6% of total deaths) (Norman et al. 2007; Puoane et al. 2008).

Current methods to control non-communicable diseases in South Africa have not been particularly effective. Programs which aim to educate the population about the associated risk factors and the importance of early diagnosis have not been strategically implemented which has rendered key target populations without access to these campaigns, particularly in rural areas where infrastructure is poor (Puoane et al. 2008). In addition, the practice of routine screening and annual physical health examinations has not been adopted by both health workers and the population at large (Puoane et al. 2008). The impact of chronic non-communicable disease extends to the individuals facing disease, their households as well as the health system. These diseases tend to affect individuals when they are in their most economically productive years which reduce their households earning capacity through a diminished ability to engage in productive labour (Puoane et al. 2008). Further, chronic disease treatment places a heavy burden on the already strained health system particularly due to the longevity of treatment and the associated financial investment (Puoane et al. 2008)

Despite the fact that deaths relating to injury and violence do not feature among the Millennium Development Goals, South Africa carries a substantial health burden related to these causes which creates an enormous demand for medical care and rehabilitation services (WHO 2011b). Within the country, approximately 3.5 million people will seek health services for both intentional and unintentional, non-fatal injuries annually, of which 50% are predicted to be due to interpersonal violence (Harrison 2009). When combined, violence and traffic injuries account for 75% of death and injury from external causes and represent 6.5% and 3.0% of the total disability-adjusted life years of the South African population, respectively (Harrison 2009; Coovadia et al. 2009). Despite a decline in the homicide rate over the past two decades, rates of sexual assault and rape, as well as death rates from traffic injuries continue to escalate (Harrison 2009).

The constitution of South Africa requires that the government work towards the progressive realization of the right to health however, eighteen years after the democratization of the country, massive health inequities continue to exist (Coovadia et al. 2009). The burden of illness, injury and mortality disproportionately falls upon certain groups, who often “live, work and travel in unsafe environments; benefit less from prevention efforts; and have less access to high-quality treatment” (WHO 2011b, p.

20). Disease has a wide array of risk factors however, those that are of primary interest to policy makers are those which are modifiable including “individual and community influences, living and working conditions and socio-cultural factors” (Puoane et al. 2008, p. 75). Racially, prevalence of HIV among Indian South Africans, falls between 0.6% and 1.9% whereas the prevalence of HIV among Black South Africans has been found to be 13.3%; “in 2002, infant mortality [was] 7 per 1000 in the white population and 67 per 1000 in the black population, [further,] life expectancy for white adult women was 50% longer than it was for black women” (Coovadia et al. 2009, p. 824). Inequities across provinces are also evident: in 2000, the provincial mortality rate for children under 5 years in the Western Cape Province was 46 per 1000 live births compared to a substantially higher rate of 116 per 1000 live births in the KwaZulu-Natal province (Coovadia et al. 2009). Even intra-provincial infant mortality rates show a high degree of health inequity whereby there exists a threefold difference in infant mortality between middle-class communities and squatter communities (Coovadia et al. 2009).

The marked differences in the rates of disease and mortality in South Africa can be seen between races, socio-economic groups, provinces and gender which reflect differences in access to basic household living conditions and other determinants of health (Coovadia et al. 2009). South Africa’s apartheid past continues to influence inequities in its health, services, and resources (Harris et al. 2011). Even with a host of policies directed at ensuring water, housing, electricity, sanitation and health care is provided to all, these services have become highly unreliable and insufficient through poor implementation and management (Coovadia et al. 2009).

The South African Health Sector

Though food, employment, education and housing- the conditions by which people live- will strongly affect health and must be prioritized by the state; access to health services are a critical component of addressing the ways in which individuals live and die (WHO 2010a). The agenda for post-Apartheid South Africa’s health policy was born out of a need to address the highly fragmented health system which existed through colonialism and apartheid. By 1994, this system had been weakened by disempowerment, discrimination and underdevelopment whereby budgets were overspent, human and financial resources poorly distributed and large inequalities in infrastructure were evident between geographical regions (Coovadia et al. 2009).

Since then, the South African health sector has experienced significant restructuring. The fourteen health administrations of the pre-1994 state were consolidated into one national and nine provincial health departments (Coovadia et al. 2009). The National Department of Health provides a framework for health policy while provincial health departments are responsible for developing their own respective policy within the confines of the national framework (Coovadia et al. 2009). Focus was shifted toward primary health care delivery through the demarcation of health districts as an integrated, comprehensive approach to servicing the health needs of the country, particularly for those that were disadvantaged (Coovadia et al. 2009). The broad framework for planning and implementing this program was initially provided by the relevant articles of the 1995 African National Congress (ANC) National Health Plan, the 1996 National Drug Program, the 1997 White Paper for the Transformation of the Health System in South Africa and more recently by the 2004 National Health Act.

The Public Sector

The public health system is led by the National Department of Health which is responsible for overall health policy and co-ordination and is largely financed by general taxation. Implementation and delivery of health services is through the nine provinces and 53 health districts which are divided into 284 municipalities (local government authorities). The provinces provide mainly curative hospital services through tertiary and regional hospitals; district and municipal government provide primary health care and preventative and promotive health services through district level hospitals and nurse-driven services at community health centres (Coovadia et al. 2009). Approximately 84% of the total population of South Africa, an estimated 42.50 million people, is reliant on the public sector for health services (Retchin et al. 1997; South African Department of Health 2002). Nonetheless, only 30% of South African health care facilities belong to this sector (Retchin et al. 1997; South African Department of Health 2002).

Since 1996, primary health care has been free for all South African citizens marking a significant step towards making health care accessible to all (Harrison 2009). Furthermore, clinic infrastructure has been significantly expanded through the Clinic Upgrading and Building Program (CUBP) (1994) and the Hospital Rehabilitation and Reconstruction Program (1998) (Harrison 2009). These initiatives have seen the establishment of eleven district and regional hospitals, three academic complexes, 1345 new clinics and the upgrade of 263 clinics through equipment replacement and expansion, particularly among rural

and marginalized communities (Coovadia et al. 2009; Harrison 2009); “the proportion of Africans who reported travelling fifteen minutes or less from home to health services increased from just over a third (36.3%) to above half (54%) between 1995 and 1998” (Harrison 2009, p. 16). Furthermore, the past decade has seen improvements in the parity of district health expenditure; between 2001 and 2008, “the ratio between the district with the highest and lowest public per capita spending dropped from 9.3 to 3.3 – a considerable improvement in the equitable allocation of public resources” (Harrison 2009, p. 16).

Despite these successes, key challenges remain. With the projected growth in both the incidence rates and complexities of both communicable and non-communicable disease, there is a corresponding need for a rational, comprehensive approach to the simultaneous prevention and treatment of these conditions which will require greater parity in resource allocation as well as co-ordination between all levels of the public health sector (Harrison 2009). A considerable body of research has also highlighted the inefficiencies which exist in the South African public health sector as a result of poor quality of care and low health worker morale which necessitate monitoring and quality improvement initiatives through education and training (Harrison 2009). A related concern is the persistent health worker shortages faced by the public sector, more pronounced in rural areas despite rural skills allowances and community health service which is mandatory for the majority of health workers after the completion of their studies (Harrison 2009). Further, poor implementation has repeatedly been cited as a principal reason why the gains of the effectively designed, evidence-based and internationally-praised South African health policies have not been translated to the population, which demands improved planning and management of policy implementation as well as harmonious leadership across provinces (Coovadia et al. 2009)

The Private Sector

The private sector services the health care needs of 16% of South Africans, an approximated 8.10 million people, through 70% of the health care resources which exist in the country (Retchin et al. 1997; South African Department of Health 2002). Primarily composed of general practitioners, medical specialists and private hospitals, the private sector is predominantly funded by voluntary medical schemes (encompassing 66% of total private expenditure on health) and out-of-pocket payments (OOP)

(encompassing 29.7% of total private expenditure on health) (WHO 2011b). Since 1998, the proportion of South Africans belonging to a medical scheme has remained fairly constant at around 14% of the population; so too have the contributions made by these members (Harrison 2009; Health Systems Trust 2012). Nonetheless, there has been a significant decline in the benefits paid by most medical schemes, which has led to higher out-of-pocket expenses for members seeking treatment in the private sector (Harrison 2009). Another notable trend in medical aid membership has seen many members opt for lower risk schemes; between 2007 and 2009, a 19% increase in membership to low-risk medical aid schemes was observed and a corresponding 27% decline in membership to high-risk medical schemes (Harrison 2009). The private sector is not anticipated to grow considerably unless the incomes of the general population grow (Harrison 2009). As an alternative mechanism for growth, the private sector has become involved in service delivery within the public sector through Public-Private Interactions (PPIs) (Harrison 2009); these interactions have notably included “contracts with both profit and non-profit providers supporting the delivery of tuberculosis, psychiatric and secondary level hospital care for public patients” (Wadee et al. 2004, p. 7).

Private care in South Africa has been criticized for being unequally distributed and responsible for the maldistribution of health workers in the country; approximately 70% of private hospitals exist in three of the nine provinces with 38% located in the Gauteng Province (Johannesburg and Pretoria) alone and; approximately 60% of all South African doctors and 80% of all dentists and pharmacists are employed by the private sector which serves only a small fraction of the population (Coovadia et al. 2009; Retchin et al. 1997).

Health Funds

According to the WHO, health expenditure in South Africa constitutes 8.2% of the nations' GDP, a value which has modestly increased over the past decade (WHO 2011b). Between 2005 and 2006, general taxation accounted for approximately 40% of total health care funds, medical aid contributions contributed 45% and out-of-pocket payments contributed 14% of total health care funds (Health Economics Unit 2009). Despite the progressivity of South African health care financing, whereby “the richest 20% of the population contribut[e] about three times the proportion of personal income than the poorest 60% of the population” (Harrison 2009, p. 24); the private sector is financed

disproportionately when compared to the public sector which has a significant impact on the benefits of health services which are available to the users of each respective sector (Harrison 2009).

Between 2008 and 2009, expenditure per person was about 5.4 times higher than public sector expenditure per person (Health Systems Trust 2012). In totality, general government expenditure on health was 39.7% of the total expenditure on health whereas general private expenditure on health represented 60.3% of total expenditure on health (WHO 2011b). Evidently, there is a substantial difference in resource availability between public and private sectors particularly significant when one considers that the public sector has a far smaller resource base to serve a population approximately four times the size of the population served by the private sector. As made evident by the health indicators discussed earlier, the burden of disease is much higher among the marginalized and poor who are largely dependent on the public system for health care; when the resources available to the public health sector is considered, it can be said that the distribution of benefit from health services is unfairly distorted toward wealthier groups and is inequitable (Harrison 2009). As a result, South Africa is now on a trajectory toward a National Health Insurance scheme to allow cross-subsidization between the rich and poor as a means of reversing these trends and promoting equity in health service delivery (Harrison 2009).

Background of TB in South Africa

South Africa currently has the third-highest TB burden in the world with TB notification rates increasing fivefold over the last twenty years (Wood et al. 2011). In 2008, TB incidence was an estimated 940 cases per 100 000 people (Mukinda et al. 2012). Despite the adoption of the DOTS strategy in 1996 and significant investments in TB control, the case detection rate remains less than 60% with treatment success rates in 2008 at 76%, falling short of the WHO targets of 70% and 85%, respectively (Mukinda et al. 2012). The TB notification rates for a single health district in South Africa (Cape Town Metropolitan) represent double the number of TB cases reported in the United States of America (Wood et al. 2011).

A serious contributor to the burden of TB in South Africa has been the emergence of multi-drug resistant (MDR) strains of the mycobacterium tuberculosis bacilli, the organism which causes TB (Fourie 2011). Those that become infected with MDR are subject to extended, complex and extremely expensive treatment regimens which have poor success rates and often fatal outcomes (Fourie 2011). It has been estimated that treatment for MDR-TB costs 100 times the cost of treating drug-susceptible TB (Fourie

2011). Furthermore, the impact of the HIV/AIDS epidemic has been considerable; HIV/AIDS infected individuals possess weakened immune systems and are therefore highly at risk to acquire TB. In 2007, approximately 40% of all notified TB cases in South Africa were tested for HIV/AIDS infection and 73% were estimated to be positive (Wood et al. 2011). Over the next five years the epidemiological profile of TB in South Africa is likely to show increasing rates of infection, more pronounced in the provinces of KwaZulu-Natal, Mpumalanga and Gauteng, which have the fastest-growing HIV infection rates in the country (Fourie 2011).

The TB burden faced by the country is largely a product of the failures and injustices which took place in the country's past. Until 1995 which saw the establishment of the National Tuberculosis Register, national cure rates were unknown and control efforts were unable to challenge poor performance (Fourie 2011). Estimates by the Medical Research Council's (MRC) National Tuberculosis Program have indicated that if control efforts do not improve, an anticipated 3.5 million new cases of TB will develop with approximately 90,000 deaths over the next decade (Fourie 2011).

South Africa's Response to TB

The National Tuberculosis Control Program (NTCP) is the South African plan for TB control and was revised in 1995 based on the WHO's Directly Observed Treatment, Short -Course (DOTS) strategy which necessitates: (1) a sustained government commitment to prioritize TB control; (2) the diagnosis of TB through sputum microscopy; (3) standardized and supervised treatment in a supportive environment; (4) uninterrupted drug supply and; (5) regular monitoring of patients and health systems (South African Department of Health 2004). This program replaced the non-standardized short-course chemotherapy which had been available for several years. Since then, recommendations by the WHO's Stop TB Campaign and the Global Plan to Stop TB have modernized TB control within South Africa through: new and improved TB drugs (with shorter periods of treatment); superior TB diagnostic tools; improved TB registration mechanisms and; clear performance targets. "The recommended treatment regimen for newly diagnosed, drug-susceptible TB consists of a 2-month intensive phase of isoniazid, rifampicin, pyrazinamide and, optionally, ethambutol, followed by a 4-month continuation phase of isoniazid and rifampicin, administered daily" (Van den Boogaard et al. 2011, p. 693). The most recent objectives of the NTCP (for the period 2007-2011) are:

1. To strengthen the implementation of the DOTS strategy;

2. To address TB and HIV, MDR and XDR-TB;
3. To contribute to health systems strengthening;
4. To work collaboratively with all care providers;
5. To empower people with TB as well as communities;
6. To coordinate and implement TB research
7. To strengthen infection control

(South African Department of Health 2007)

The NTCP core package and essential activities are outlined in Figure 1. The NTCP involves all levels of health governance: the national level - through the co-ordination, facilitation and evaluation of TB services for the whole country; the provincial level – through the implementation and budgetary activities of TB service delivery and; the district level for the management of primary health care (Western Cape Department of Health 2004).

LITERATURE REVIEW

Introduction

TB treatment remains one of the most cost-effective treatment regimens for disease and when administered appropriately is able to cure patients and prevent transmission (Lönnroth et al. 2010). Despite the long-standing existence of effective TB treatment and its delivery through the WHO's Directly Observed Treatment, Short -Course (DOTS) strategy, TB has yet to be controlled globally and has persisted as a serious epidemic within South Africa where the incidence of the disease is currently estimated to be 940 cases per 100,000 people (Mukinda et al. 2012). The dangerous interaction between HIV/AIDS and TB, the escalating problem of drug-resistant TB and the social determinants of the disease have contributed to the gravity of this situation.

According to the WHO (2003), poor adherence to anti-tuberculosis medication is among the most significant barriers to its global control (WHO 2003). This is particularly due to the fact that TB is a communicable disease and as a result, poor adherence to treatment has implications at both the individual and community levels through morbidity, mortality and drug resistance (WHO 2003). The objective of this literature review is to summarize research that has examined the nature of adherence

to anti-tuberculosis therapy within South Africa and other comparable settings. Specifically, the objective is the gain insight into the ways in which the availability, affordability and acceptability of TB treatment can shape adherence and to understand the consequences of non-adherence to treatment.

Defining Adherence

There have been a range of ways in which adherence has been defined in the research and policy landscape. By accepting that the existence of efficacious treatment alone does not guarantee positive health outcomes and that poor administration and continuation of treatment threatens its effectiveness, it becomes particularly important to understand (and address) the factors which govern how an individual consumes and continues therapy for health conditions over a period of time (Volmink & Garner 2007). This is especially crucial for chronic, communicable disease where reduced treatment effectiveness has implications for the individual and the communities to which they belong through increased and prolonged infectiousness, drug resistance, relapse and death (Volmink & Garner 2007).

Over the past two decades, there has been a paradigm shift which has seen increased emphasis on the empowerment and autonomy of the patient in the patient-provider interaction. As a result, patients are no longer seen as "passive, acquiescent recipient[s] of expert advice" (WHO 2003, p. 3). Patients have become active collaborators in the treatment process (WHO 2003). Adherence, therefore, is not solely concerned with taking prescribed medication or following medical direction (i.e.: medication adherence), though these are important dimensions of the concept. Treatment adherence broadly encompasses the extent to which all therapeutic behaviours which have the capacity to improve the health outcomes of an individual correspond with the recommendations of the provider (WHO 2003). In much of the literature which examines adherence, patient-related factors are blamed for poor adherence and there is a propensity for researchers to neglect the role of the provider and the wider health environment (WHO, 2003). The WHO (2003) asserts that the quality of the treatment relationship is an important determinant of adherence, effective when: (1) an atmosphere is created in which alternative therapeutic means are explored; (2) the regimen is negotiated; (3) adherence is discussed and; (4) follow-up is planned (WHO 2003). As aptly summarized by Annik Rouillon (former Executive Director of the International Union Against Tuberculosis and Lung Diseases (IUATLD)): "To default is the natural reaction of normal, sensible people: a person who continues to swallow drugs or have injections with complete regularity in the absence of encouragement and help from others is the abnormal one" (Rouillon 1972; Udwadia & Pinto 2007, p. 104).

Political Commitment	<ul style="list-style-type: none"> • Sustained political leadership at all levels of the political arena • Adequate and sustained human and financial resource allocation • Greater oversight and formal review of TB performance • Endorsement and implementation of all national TB guidelines by all stakeholders
Case Detection through Smear Microscopy & Cultures	<ul style="list-style-type: none"> • High quality, accessible diagnostic services through sputum microscopy for TB suspects and patients nationally (with transport networks for sputum collection where access is limited) • Adherence to internationally recommended diagnostic practices while exploring use of new tools for rapid diagnosis of TB • A National TB Laboratory Reference Laboratory to: regulate proficiency in and quality of all TB laboratory tests; train personnel; conduct research and surveillance
Regular, Uninterrupted Drug Supply and Management	<ul style="list-style-type: none"> • Adequate supplies of quality TB drugs at facility level with additional buffer (safety) stocks • Health workers proficient in drug stock management • System to monitor drug supplies at facility levels to be developed. • Use of second-line drugs for treatment of drug-resistant tuberculosis must be protected
Supervision & Patient Support	<ul style="list-style-type: none"> • Continuity of DOT with standardized short course chemotherapy regimens which facilitate humane and empathetic patient treatment • Coordination and monitoring of Community Caregivers and NGOs providing TB care • Patient/ family education and counseling on an ongoing basis on: Early recognition of symptoms; Treatment guidelines & side-effects; smear microscopy; Importance of treatment completion • Engage services of private sector, NGOs and Traditional healers
Standardized Reporting and Recording System	<ul style="list-style-type: none"> • Data collected daily at facility level by coordinator for data entry into Electronic TB Registry at sub district level. • Community based monitoring and evaluation tools • Validation conducted at facility, sub district, district and provincial levels. • TB data collection tools available at all facilities comprising: The TB register; Suspect registers; Patient & Facility cards; Referral forms
TB & HIV	<ul style="list-style-type: none"> • Functional integration of TB and HIV services according to best practice model(s) through: Increased HIV testing uptake by TB patients; ART for all co-infected patients. • Training of facility staff in clinical management of co-infected patients • Early diagnosis of HIV in TB patients through provision of provider initiated testing • Cultures conducted for all HIV positive TB suspects
MDR & XDR-TB	<ul style="list-style-type: none"> • 1st line Drug Susceptibility Testing (DST) for high risk groups; 2nd line DST for confirmed MDR-TB patients. • All confirmed XDR-TB & MDR-TB patients referred to MDR-TB Unit; ongoing care at nearest health facility; Monitored by MDR-TB Unit for 24 months; psychosocial support; • Strengthened infection control in all health care facilities by training, monitoring and improved ventilation. • Increased capacity at XDR-TB units to provide recreational, occupational and educational support.
Patient Empowerment	<ul style="list-style-type: none"> • Adherence to a patient's charter which outlines the rights and responsibilities of people with TB • Empower people with TB, their families and communities through knowledge. • Development and dissemination of information, education and communication (IEC) materials on the patient's charter

Figure 1: Summary of NTCP Core Package & Activities (Western Cape Department of Health 2007b)

3. Deviation from the prescribed treatment in another way, including brief treatment interruptions and under- or overdosing

(Farmer 1999; Van den Boogaard et al. 2011, p. 694)

Currently, however, there exists no empirical definition for non-adherence which delineates the point at which a patient is said to be non-adherent. Strategies which have aimed to do so have been complicated by the fact that standard TB treatment guidelines allow a certain level of flexibility with regards to intermittent dosing i.e. whether treatment is administered daily or weekly (Munro et al. 2007; WHO 2003). Further, although “premature termination of treatment increases the risk of treatment failure and relapse, the exact relationship between this risk increment and the duration of treatment until termination is unknown”(Van den Boogaard et al. 2011, p. 693).

The Debate of Directly Observed Treatment vs. Self-Supervised Treatment

Since the acceptance of TB as a worldwide emergency in 1993, the Directly Observed Treatment, Short - Course (DOTS) strategy has been the main mechanism by which the WHO’s Stop TB Campaign and the Global Plan to Stop TB aims to guide national TB policy to reach the Millennium Development Goal of “reduc[ing], by 2015, the prevalence of and deaths due to TB by 50% relative to 1990 and revers[ing] the trend in incidence” (WHO 2010a, paragraph 1; Lawn & Zumla 2011, p. 64). The DOTS strategy is based on five key covenants which have been discussed earlier. One of the most important aspects of the DOTS strategy is that treatment is supervised whereby an appointed person (health worker, community volunteer or trained family member) directly observes the patient swallowing their anti-tuberculosis medications over approximately six to eight months – the average duration of treatment for drug-susceptible TB (Volmink & Garner 2007). DOT was first adopted in the 1960s in certain areas of India and Hong Kong and since then has been widely implemented in most countries with national tuberculosis treatment programs (Volmink & Garner 2007).

A number of studies have argued that the DOTS strategy is essential and is the most effective way of preventing relapse and the development of drug resistance; patients are able to be closely supervised and are coerced into adherence through peer pressure and other social influences (Volmink & Garner 2007). However there are also a number of claims that the DOTS strategy is no more beneficial than self-supervised treatment; these critics also assert that directly observing treatment can actually promote non-adherent behaviour by reverting to the former view of patients as passive recipients of treatment (Volmink & Garner 2007). As explained by Volmink and Garner (2007), “the disadvantages

associated with DOT are that it moves away from adherence models of communication and cooperation between patient and provider... [and] may make adherence worse if it is rigidly applied in an authoritarian setting or where people are expected to travel considerable distances to have their treatment supervised" (Volmink & Garner 2007, p. 3). Furthermore, where caseloads are particularly high, the resources required to sustain the DOTS strategy as a national TB treatment program are substantial (Volmink & Garner 2007).

DOTS programs vary widely across the world as the framework provided by the WHO is sufficiently broad to allow for individualized interpretations; as yet, "the essential components for DOT strategy success have not been systematically established through randomized trials" (Moonan et al. 2011, p. 6). This has made it increasingly difficult to compare studies (Moonan et al. 2011). Moonan et al (2011) describe two different approaches to the implementation of the DOTS strategy; although both adhere to the guidelines put forth by the WHO, the outcomes of each program are significantly different (Moonan et al. 2011). In the first case, the authors describe a program which serves a poor population using a "maximally restrictive" (Moonan et al. 2011, p. 6) interpretation of DOTS whereby patients are mandated to visit a facility five times weekly for approximately twelve weeks and three times weekly thereafter until cured (Moonan et al. 2011). In the second case, the authors describe a program which has used an alternative interpretation of DOTS whereby medications are delivered to the homes of patients for a period of two months and thereafter, patients are self-supervised until cured (Moonan et al. 2011). In the former case, over 40% of patients did not complete their treatment whereas in the latter, the program achieved cure rates of over 85% (Moonan et al. 2011).

In 2007, Volmink and Garner (2007) conducted a Cochrane Review to compare DOT with self-supervised treatment for clinically active TB (Volmink & Garner 2007). According to their findings, in both clinic-based DOT and community-based DOT (i.e. by a family member or community volunteer) treatment adherence and outcomes are similar to those of self-supervised treatment (Volmink & Garner 2007). Volmink and Garner (2007) suggest that the benefits that have been linked (through observational studies) to the DOT strategy are more likely the result of the cumulative effect of a range of interventions aimed at improving adherence (Volmink & Garner 2007). In a similar vein, Udwadia and Pinto (2007) suggest that the success of the DOTS strategy can be attributed to the major investments in infrastructure that is required for the program to be administered, rather than the fact that treatment is directly-observed (Udwadia & Pinto 2007).

In 2009, Volmink and Garner (2007) updated their findings through an analysis and review of randomized and quasi-randomized trials that had not been previously available. Nonetheless, their conclusion remained the same; as yet, there is no assurance that the use of DOT in low and middle income countries improves cure rates or completion of treatment when compared to self-supervised treatment (Volmink & Garner 2007). A cluster-randomized trial in South Africa found that support and motivation by a health worker was more effective at ensuring treatment adherence than DOT-based services (Clarke et al. 2005; Volmink & Garner 2007). The authors urge governments to refocus resources away from DOT strategies to interventions which have been proven to improve adherence such as patient support, motivation and incentives until more is known about the situations in which DOT will be most effective (Volmink & Garner 2007).

The DOTS strategy is currently “in the process of shifting from being a rigid model involving observation of drug swallowing to one that includes an array of incentives and enablers for supporting the patient” (Volmink & Garner 2007, p. 7; Macq et al. 2003). Given that those affected by TB are generally poor and face a number of barriers to treatment adherence, it has been suggested that programs which target a reduction in social and health system barriers may be far more effective in improving adherence and cure rates (Volmink & Garner 2007). Rates of non-adherence to treatment are required to fall below 10% in order to achieve treatment success of 85%, one of the health-related indicators of the Millennium Development Goals (Western Cape Department of Health 2002)

Factors Influencing Adherence

What is consistent from the majority of literature which examines adherence to TB treatment is the fact that adherence cannot be predicted or controlled by a single factor. Likewise, non-adherence is a “complex, dynamic phenomenon with a wide range of interacting factors impacting treatment-taking behaviour” (Munro et al. 2007, p. 1243). Adherence barriers take effect against an array of facilitating factors, and the final decision about treatment adherence depends on which factors predominate (Gebremariam et al. 2010). Therefore, efforts which aim to improve adherence, treatment outcomes and more widely, to control the global TB burden, require a better understanding of the specific barriers to and facilitators of adherence to TB treatment, and of patient experiences of taking treatment (Munro et al. 2007). In the context of TB, adherence to and the success of treatment are hinged on assured daily access to treatment services for a prolonged treatment period. For the purpose of this discussion, these

specific barriers and facilitating factors have been categorized based on the three dimensions of access: acceptability, affordability and availability, as outlined by the most recent contributions to the study of access (McIntyre et al. 2009; Thiede et al. 2007)

Acceptability

There are a number of documented ways in which the acceptability of TB treatment affects patient adherence. These include: knowledge about TB and belief in the efficacy of the medication; cultural belief systems; the nature of relationships between the health provider, social networks and the patient and; regimen complexity (WHO 2003).

In a systematic review conducted by Munro et al (2007), the authors sought to understand the factors which were considered to be important determinants of TB medication adherence by reviewing a number of qualitative studies (Munro et al. 2007). The authors reported that the nature of the interaction between the patient and the provider was a significant influence on adherence to TB treatment (Munro et al. 2007). Poor follow-up and maltreatment by providers resulted in non-adherence especially where patients were reprimanded for missing appointments (Munro et al. 2007). Qualitative findings from Khan et al (2005) also illustrate the negative attitudes by health workers to TB patients enrolled in a DOTS program in Pakistan whereby facility staff reported a lack of commitment to treatment, a high degree of cynicism and little concern for the outcomes of the patients (Khan et al. 2005).

Kaona et al (2004) note that discrimination on the basis of TB infection occurs within many health facilities and exacerbates problems with adherence to tuberculosis drug taking (Kaona et al. 2004). Where there is little privacy between patient and provider, patients resist collecting medication due to discriminatory behaviour by health care providers (Kaona et al. 2004). Correspondingly, where patient-provider interactions were reported to be positive, patients were more adherent to treatment (Munro et al. 2007). In certain regions of Columbia and in Middleburg, South Africa, health workers reported high intrinsic motivation to treating TB and developed close relationships with patients which lead to increased patient motivation to complete treatment (Macq et al. 2003).

Another key finding by Munro et al (2007) related to the nature of direct-observation. A number of studies which were reviewed by the authors reflected how patients saw direct-observation negatively and felt as though it indicated distrust between the provider and themselves (Munro et al. 2007). Some patients likened the process of direct-observation to serving a sentence within a correctional institution (Munro et al. 2007). This finding is consistent with those from a South African trial which compared DOT to self-supervised treatment whereby direct-observation was seen to have a demoralizing effect on patients and a resultant negative effect on adherence, particularly among those who were undergoing treatment for a second time (Zwarenstein et al. 1998; Volmink & Garner 2007). Udwadia and Pinto (2007, p. 103) further cement the effects of direct-observation on the interaction between the patient and provider; according to the authors, DOT is viewed by patients as being "humiliating, authoritarian and an invasion of privacy" (Udwadia & Pinto 2007). Approximately 45% of the patients reviewed refused to allow a health facility worker to observe the intake of medication, most often citing that they were responsible enough to do so without observation and that they did not trust public services (Udwadia & Pinto 2007).

The impact of knowledge and beliefs surrounding treatment practices and efficacy of treatment is also well documented. A large number of patients will cease treatment when their symptoms have been alleviated or interrupt treatment when and if their symptoms worsen (Munro et al. 2007). The majority of studies reviewed by Munro et al (2007) claimed that a primary reason for this is that patients are not correctly informed by providers as to the nature of TB, the duration of treatment and the consequences of non-adherence (Munro et al. 2007). Further, many patients doubt the efficacy of the medication and the validity of the diagnostic tools which reflects low levels of confidence in public health services as well as a high degree of fear and denial surrounding the TB diagnosis (Munro et al. 2007). Khan et al (2005) found that the two most significant contributors to TB treatment default in Pakistan were: (1) a lack of belief in the efficacy of the drugs and; (2) the belief that the drugs were harmful (Khan et al. 2005). In an ongoing study of the knowledge and perception of DOTS in Delhi, India, only 14% of patients were aware of DOTS, particularly pronounced among the illiterate and marginalized who form a large proportion of the TB population (Udwadia & Pinto 2007). Correspondingly, where patients understand and fear the negative consequences of non-adherence, they are more likely to choose to complete the treatment regimen (Munro et al. 2007).

Vulnerability to ostracism and the stigma associated with TB is a considerable acceptability-related barrier to treatment adherence (Udwadia & Pinto 2007). A study of TB treatment adherence in the Eastern Cape province of South Africa revealed that the majority of individuals (90%) within the lay-community believe that irresponsible individuals are to blame for the TB epidemic (Cramm et al. 2010). The same focus group discussions revealed a widespread belief that those who acquire TB through drinking and smoking are deserving of the fatal consequences of the disease and that TB patients are less respected within their communities; these findings are indicative of a high level of susceptibility to stigma for TB patients, particularly within this setting (Cramm et al. 2010).

Munro et al (2007) also document the influence of stigma. According to their review, TB patients will often hide their diagnosis and harbour feelings of guilt and shame because of the disease (Munro et al. 2007). TB patients have been seen to evade treatment because of fear of disclosing their TB-status to their employers, often rendering them unable to purchase medications or take time off work to attend health facilities (Munro et al. 2007). In Ethiopia, patients reported being pointed at and excluded from social events when their TB status became known in their communities (Gebremariam et al. 2010). The fear of stigma from community members has meant that many refuse to seek treatment at facilities within their respective communities and will either avoid treatment altogether or face high costs to travel to distant clinics to avoid being identified (Gebremariam et al. 2010; Macq et al. 2003)

Availability

The organization and structure of TB services have the capacity to influence adherence to TB treatment in a variety of ways. Shargie and Lindtjorn (2007) conducted a cohort study to determine the extent and predictors of non-adherence to TB treatment in southern Ethiopia (Shargie & Lindtjorn 2007). Their findings indicate that the majority of factors which contribute to treatment default were concerned with physical access to health facilities, particularly in rural settings (Shargie & Lindtjorn 2007). Specifically, the authors note that the longer the distance between the patient's home and the treatment centre, the more likely patients were to forgo daily-DOTS visits; 50% of patients who lived beyond a two hour walking distance of the facility defaulted on their treatment (Shargie & Lindtjorn 2007). In addition, where patients were reliant on public transport, they were also more likely to fail to complete their treatment regimen (Shargie & Lindtjorn 2007). These findings are consistent with the results of the systematic review conducted by Munro et al (2007) on the determinants of treatment adherence

whereby long distances and a lack of available transport were regularly cited as the primary reasons for default in the majority of the literature reviewed (Munro et al. 2007).

The burden of travelling considerable distances to facilities is exacerbated by the fact that TB patients are typically subject to severe, debilitating symptoms which often renders them too frail and weak to travel alone. Gebremariam et al (2010) note that many patients express that this burden extends beyond themselves whereby family members are required to accompany them to the facilities and it is often easier to skip visits altogether (Gebremariam et al. 2010). Similarly, Sagbakken et al (2008) found that patients walked on average two hours to reach the facility where they were receiving their treatment, often describing the journey as extremely arduous, frequently vomiting and fainting while travelling (Sagbakken et al. 2008). These patients were forced to wait for several hours before being seen by a health worker due to poor management systems which requested all TB patients arrive at the clinic during the same period of time (Sagbakken et al. 2008). In the same way, findings from the systematic review conducted by Munro et al (2007) found that long waiting times, queues and inconvenient appointment times (or opening hours) lead to high levels of treatment default (Munro et al. 2007).

In efforts to decentralize treatment and reduce the physical barriers to treatment adherence, many national governments have provided systems which facilitate the delivery of medications to the homes of patients by appointed community members or community health workers (Macq et al. 2003). In practice, these systems have been seen to present their own range of barriers. In Pakistan, rather than delivering medications to the patient's homes, many appointed community members force patients to travel to their own private residences to collect their medications (Khan et al. 2005). Furthermore, patients expressed that they would prefer to opt out of this arrangement out of fear of being identified as a TB patient by their respective communities (Khan et al. 2005).

The WHO (2003) has stated that the availability of expertise also affects adherence to treatment; DOTS programs are often facilitated by ambulatory health care units which are organized to effectively accommodate acute illnesses rather than chronic illnesses that require long-term care (WHO 2003). As a result, within these settings, the staff have been seen to lack the expertise to develop long-term illness management plans and will place little importance on patient follow-up (WHO 2003). All health professionals included in the qualitative analysis by Gebremariam et al (2010) agreed that DOT with

daily supervision is a demanding task for most patients, especially for those who are HIV positive and are required to attend clinics for ART in addition to TB treatment (Gebremariam et al. 2010). Many health workers likened the process of DOT to patient punishment and conceded that the DOT strategy is too rigid, not flexible to the daily schedules and priorities of the patients they treat (Gebremariam et al. 2010).

Affordability

Given that national TB treatment programs are largely free at the point of service, affordability-related factors which influence adherence are most often related to: (1) the direct costs of transportation; (2) extraordinary dietary requirements as a result of the illness and/or treatment related side-effects and; (3) the indirect costs of productive time losses incurred while travelling and receiving daily DOT.

In 2008, Sagbakken et al (2008) explored the barriers and enabling factors to TB treatment in Ethiopia, concluding that the economic burden of treatment is a key determinant of treatment adherence through a dynamic process of interaction between individuals, their households, family members, social networks and employers (Sagbakken et al. 2008). Through a series of in-depth interviews and focus group discussions, the authors note that employment-related factors significantly restrict an individual's ability to remain in treatment, particularly among those referred to as 'daily labourers' (defined as an individual who is not employed but convenes with other individuals to compete to be hired for the day) (Sagbakken et al. 2008).

Gebremariam et al (2010) also discovered that DOT was particularly challenging for those patients who had irregular jobs (Gebremariam et al. 2010). Many individuals in the private sector lost employment upon diagnosis due to the time-consuming nature of the treatment available to them as well as an inability to continue working because of severe symptoms of illness, and daily labourers were no longer able to compete with their healthier counterparts (Sagbakken et al. 2008). These effects also resonated among family-members who accompanied individuals to treatment facilities (Sagbakken et al. 2008). An important consideration is the fact that time costs represent different burdens to each gender whereby work-related time costs represent more of a barrier to men and time costs relating to family responsibilities represented more of a barrier to adherence for women (Khan et al. 2005).

Factors which relate to the cost of transport are associated with significant barriers to adherence; many individuals discontinued treatment as they were unable to afford transportation and were not strong enough to walk to treatment facilities which were usually a considerable distance away (Sagbakken et al. 2008). This finding is consistent with those of Gebremariam et al (2010) who noted patients having to sell off their belongings (such as jewellery and articles of clothing) in order to afford transportation costs to TB treatment facilities. Where facilities are a considerable distance away, patients often face additional travel costs for provisions during travel such as lodging and food, the enormity of which can determine whether or not a patient will adhere to treatment (Macq et al. 2003).

Sagbakken et al (2008) found that the majority of respondents prioritize their employment and income, interrupting or ceasing their treatment regimens, to ensure that they are able provide food to their respective households (Sagbakken et al. 2008). It is estimated that an adult suffering from TB loses approximately three to four months of productivity and the household income experiences a reduction of about 30–40% (Udwadia & Pinto 2007). For those that maintained their visits to health facilities, many became impoverished and unable to afford basic foods due to the loss of income, rendering them chronically hungry with little motivation to continue treatment (Sagbakken et al. 2008). In a cross-sectional study conducted in Zambia, 11.4% of non-adherent patients cited a lack of food at home as the primary reason for defaulting on treatment while 16.4% of these patients cited a loss of will to live, reflecting feelings of hopelessness that may result from impoverishment (Kaona et al. 2004)

What is clear is that indirect and direct costs are very easily and often exacerbated by availability and acceptability barriers. In light of the burden of TB among the poor, the economic factors which influence adherence require particular attention. The role of social networks and community is often a primary determinant of a household's ability to cope with direct costs of treatment, "patients with limited access to financial or practical help from relatives or friends experience that the total costs of attending treatment exceed[s] their available resources" (Sagbakken et al. 2008, p. 4). Despite TB's association with a high degree of stigma and fear, Sagbakken et al (2008) found that during times of crisis, many individuals relied on reciprocal arrangements between households, where encouragement and shared resources, which compensated for lost income, was an important determinant of accessing and adhering to treatment (Sagbakken et al. 2008). Social support has also been deemed crucial to the treatment process in other settings; through accompanying patients who are facing debilitating symptoms, providing food and transportation funds and support while the patient is unemployed, the

social capital of an individual is a strong determinant of adherence to TB treatment regimes (Gebremariam et al. 2010; Munro et al. 2007).

Nonetheless, Sagbakken et al (2008) note that with time, levels of financial and practical support from community members diminished due to "social and financial exhaustion" (Sagbakken et al. 2008, p. 8) which was a huge concern considering the longevity of illness associated with TB, often leading to treatment termination and social exclusion (Sagbakken et al. 2008). It is also important to note that reliance on the community and family members to cope with the direct and indirect costs of attending daily-DOT visits and adhering to the TB treatment regimen is dependent on the existence of such social capital. For some, these options do not exist and the very serious consequences include untreated morbidity and premature death.

Demographic Characteristics & Adherence Behaviour

The previous discussions suggest that an interplay of factors is involved in determining whether or not a patient will adhere to the TB treatment course. Although the majority of the aforementioned factors are liable to improvement through intervention, there are a number of largely un-modifiable, patient-level characteristics which also have the capacity to create an unfavourable environment for ensuring adherence to treatment (WHO 2003). Although there are, as yet, no specific traits which are able to describe the 'typical' non-adherent patient; several traits have been associated with treatment adherence including ethnicity, gender, literacy (or education) and age (WHO 2003). Although these associations do not allow for a pragmatic or logical means of resolving them, they are extremely important in drawing conclusions about the equity of health service access (WHO 2003).

In 2006, Bam et al (2006) conducted a cross-sectional analysis on factors affecting patient adherence to DOTS in an urban region of Nepal (Bam et al. 2006). The authors established a two-fold increase in non-adherence in patients over the age of 54 years (Bam et al. 2006). They further found significant differences in non-adherence between those that were single, married and widowed or divorced, where the likelihood of default increased in a corresponding order (Bam et al. 2006). The findings of Bam et al (2006) are supported by those of Shargie and Lindtjorn (2007). Through a univariate analysis, being over the age of twenty-five was determined to be significantly associated with treatment non-completion (Shargie & Lindtjorn 2007). Other demographic factors also deemed to be significantly associated with non-completion of the TB treatment regimen included: rural residence whereby non-adherence was

more prevalent among rural respondents and; educational level, whereby literacy was associated with increased levels of adherence compared to the illiterate respondents (Shargie & Lindtjorn 2007).

Gender has also been seen to determine individual responses to treatment choices (Munro et al. 2007). Within this context, gender refers to: (1) the physiological variations between males and females and; (2) the expectations and roles that are associated with each sex, governed by the social, economic and cultural context (Diwan & Thorson 1999). With regards to TB treatment behaviours, there are two perspectives on the effect of gender on adherence.

On the one hand, researchers have described the effects of stigma on adherence behaviours in women, whereby women often face higher levels of social exclusion if their TB status becomes known, when compared to men (Connolly & Nunn 1996). For example, in India, TB-associated stigma in women has been seen to cause divorce; while male TB patients expect and receive care from their wives, married women seldom receive support from their husbands and family members (Connolly & Nunn 1996). For single women, disclosure of their TB status often lead to an inability to marry, particularly where marriage arrangements are largely a product of community participation (Connolly & Nunn 1996). These influences lead to many women avoiding treatment and hiding their symptoms, or receiving care only until symptoms have dissipated (Connolly & Nunn 1996). In a similar vein, Udwadia and Pinto (2007) describe that women face harassment from family members, fear of being unable to find a spouse and dismissal from work which collectively represent the largest impediments to adhering to DOTS in India, among women (Udwadia & Pinto 2007).

A second perspective asserts that women are in fact more adherent to TB treatment and more likely to seek treatment when compared to men (Khan et al. 2005). Khan et al (2005) demonstrate that women in Pakistan have achieved substantially higher cure rates of TB where the cure rates are 71% and 50% for women and men, respectively (Khan et al. 2005). The authors believe that women are more likely to adhere to treatment because they possess a sense of a responsibility to their household and children (Khan et al. 2005). Rather than observing pressure and harassment from family members as a barrier, Khan et al (2005) show that these forces can actually facilitate adherence to the TB treatment regimen (Khan et al. 2005).

It is important to consider that approximately 70% of the world's poorest people are female (Diwan & Thorson 1999). In addition to disproportionate poverty levels, women typically receive inferior social status within their communities, lower levels of education and face the largest barriers to seeking health care (Diwan & Thorson 1999; Connolly & Nunn 1996). Too often, TB policy assumes that adherence rates are the product of a patient's willingness to adhere (Munro et al. 2007). However, even where patients are willing, structural factors such as gender discrimination prevent them from doing so (Munro et al. 2007). As urged by the WHO (2003), interventions which are aimed at improving adherence must strategically address the wider context of the health care system (Munro et al. 2007; WHO 2003).

RATIONALE & JUSTIFICATION

Tuberculosis (TB) represents one of the most pressing global health issues and one of the greatest challenges to the health of South Africans (WHO 2011a). Despite the adoption of the DOTS strategy in 1996 and significant investments in TB control, the case detection rate remains far below the targets outlined by the WHO (Mukinda et al. 2012). The effects of the disease are particularly pronounced among the 13.3 million South Africans living in poverty (WHO 2011b). It is widely documented that these groups face higher rates of mortality and morbidity relative to their better off counterparts, yet despite their increased needs, use health services less (O'Donnell et al. 2008). With this in mind, health initiatives and policies are being focused on ways to enhance access among disadvantaged groups by prioritizing the need to understand their individual experiences of accessing health services (Whitehead 1992). In this way, poor use of essential services can be explained and addressed whereby quality of care and cultural factors which influence access can also be examined (Whitehead 1992).

This approach is particularly vital in the context of TB where the success of current treatment protocol is hinged on daily access to health care for a prolonged treatment period. The burden of non-adherence to curative TB treatment has been widely acknowledged as being a key constraint to the global control of TB. Where non-adherence is the result of unfair, unjust, avoidable or unnecessary forces, equity concerns intensify its importance. There are two primary obstacles to finding effective solutions: (1) there exists a cloud of ambiguity surrounding the mechanisms in which different levels of non-adherence impacts treatment outcomes and; (2) there is no "comprehensive and holistic understanding of barriers to and facilitators of treatment adherence" (Munro et al. 2007, p. 1230; Van den Boogaard et

al. 2011). It therefore follows that evidence-based research is needed to demonstrate in quantitative terms the nature of the interaction between the facilitating forces and barriers of adherence so that national governments are equipped to tailor the provision of treatment and health promotive interventions to ensure patients are able to complete their treatment.

OBJECTIVES

1. Describe the socio- demographic characteristics of adherent and non-adherent DOTS patients.
2. Explore the relationship between the availability, affordability and acceptability of DOTS services and patient adherence.
3. Assess the equity in accessing DOTS services across the dimensions of availability, affordability and acceptability.

METHODOLOGY

Data Source

This study will be based on data derived from Phase 1 of the Researching Equity in Access to Health Care (REACH) project, a five-year study of health system access in South Africa which commenced in 2007. The author of this thesis had no role in the study design and data collection of the REACH project. Funding for the study has been provided by a Teasdale-Corti Team Grant, administered by the Canadian International Development Research Centre (IDRC). REACH assesses equity in access to health services through an in-depth investigation into the use of three health interventions (or, 'tracers'): TB treatment services, maternal health services and antiretroviral therapy (ART) across four health sub-districts in South Africa: Bushbuckridge (Mpumalanga), Mitchell's Plain (Western Cape), Soweto Region D of the City of Johannesburg (Gauteng) and Hlabisa (KwaZulu-Natal) (Schneider et al. 2009). Phase 1 of the REACH study specifically sought to examine health service users to determine whether they reflect the population in need by socio-economic and demographic variables. A second feature of Phase 1 examines access to the three tracer health services, defined as the 'degree of fit' between service users and service providers in the availability, affordability and acceptability of services (Schneider et al. 2009). In totality, REACH endeavours to:

1. Map inequities in utilization and access nationally;
2. Identify relevant responses in the policy and practice environment and;

3. Integrate research, capacity strengthening and knowledge translation, through a variety of methodologies to strengthen the capacity to respond to health inequities in the health sector more widely.

(Schneider et al. 2009)

This study focuses on the Mitchell's Plain sub-district data set (N= 999) and specifically draws on individuals using TB treatment services (n=334). Mitchell's Plain represents an urban sub-district in the Western Cape province of South Africa. The data set was collected between 2008 and 2009 by the REACH research team, an experienced multi-disciplinary team of health economic, systems, policy and social science researchers. Mitchell's Plain has been included in this study primarily based on: (a) its geographic location, which enables comparisons to be made between and among the other urban (Soweto Region D, Gauteng) and rural sites (Bushbuckridge, Mpumalanga; Hlabisa, KwaZulu-Natal); (b) the number of facilities offering tracer services; (c) the province to which it belongs, to allow for comparisons between different provincial governance structures; (d) consultations with district health managers and local health authorities who have broad knowledge and experience with sub-districts facing access challenges and; (e) the availability of recent and reliable household and census data pertaining to the socioeconomic status of those with TB and HIV within the district (Schneider et al. 2009).

In Mitchell's Plain, multiple facilities offer TB services and each varies considerably in size and capacity. To ensure that individuals visiting larger facilities had the same probability of getting into the sample as those visiting smaller sites for treatment, a probability proportional to size method was used to choose the five facilities (Crossroads I, Lentegour, Mzamomhle, Phumlani and Weltevreden) which were included in the study. This method necessitated the use of existing data on the total number of users in each facility at the time of the data collection; further, this method allows some facilities to be sampled twice so the sample size within facilities varied slightly across the five facilities. Such a sampling approach allows for results to be generalizable to TB service users within the sub- district. Within facilities, systematic random sampling methods were used to choose respondents.

Data Collection & Conceptual Framework

The REACH project fieldwork involved two key elements: interviewer-administered, in-depth, exit interviews on access-barrier to tracer services as well as socio-demographic data and; record reviews of patient records. The two primary data collection tools used to derive this data included:

1. Patient Exit Interview Questionnaire - Tracer TB (Appendix A)
2. Record Review of Tuberculosis Services (Appendix B)

A total of 334 patients, made up of 47% males and 53% female, were interviewed across all five facilities in Mitchell's Plain. Subjects were included if they had been receiving TB treatment for at least two months, were over the age of eighteen and were deemed to be sufficiently well to participate, by facility staff.

The data collection approach was guided by a comprehensive conceptual framework of access whereby access is assessed in terms of the *degree of fit* between the needs of the population and the availability, affordability and acceptability of the health system response (Thiede et al. 2007; McIntyre et al. 2009). Under this conceptual framework, the availability (physical access factors), affordability (financial access factors) and acceptability (cultural access factors) of health services, can be empirically investigated to understand the experience of accessing services and the ensuing barriers which may exist in doing so. Furthermore, this framework can assist in developing health policy strategies that can address the barriers (Thiede et al. 2007; McIntyre et al. 2009). Each of these access dimensions can be represented by a number of clear and measurable variables which formed the basis of the questionnaire design and data collection of the REACH study.

In-depth interviews were administered by trained fieldworkers using a structured exit interview questionnaire (see Appendix A) in the language of each subject's choice. Patients were asked about the affordability, acceptability and availability of TB services and questions covered specific factors underlying these three themes. A summary of principal areas of questioning through the exit interview is provided in Table 1. The availability variables included the travel time for the patient to reach the TB-treatment facility, the time spent within the facility, whether patients were required to travel on foot and how often they were required to visit the facility to fetch their TB medications. Affordability variables incorporated coping mechanisms by asking whether or not the patient was required to borrow money in order to meet the costs of treatment and also included information on health care expenditure which was compared to the patient's overall household expenditure. With regards to the

acceptability dimension, respondents questioned primarily about their perceptions of staff attitudes, facility cleanliness, queue and the stigma of receiving and treating a TB diagnosis.

To gain a more holistic understanding of the challenges in accessing TB treatment, reviews of patient's records were also conducted for all patients who had been interviewed. In this way, service processes were also captured to enable cross-comparison with standard treatment guidelines. Record reviews were guided by a questionnaire form which was completed by the fieldworker (see Appendix B). A summary of principal areas of interest in the review of patient records is provided in Table 1

SUMMARY OF DATA COLLECTION TOOLS	
Patient Exit Interview Questionnaire - Tracer TB (Appendix A)	Record Review of TB Services (Appendix B)
Socioeconomic & Demographic	General Level Of Completeness Of Patient Record
Utilization Of TB Treatment Services	Correctness Of Clinical Management
Affordability	
Availability	
Acceptability	
Household & Dwelling	

Table 1: Summary of Data Collection Tools

Completed questionnaires were inspected by a data collection coordinator for accuracy. Once approved, responses were double entered into a data entry platform and exported to STATA/SE 11.0 for analysis.

Study Setting & Population

The Mitchell's Plain sub-district belongs to the Cape Town Metropolitan health district, located in the Western Cape Province in the south-west region of South Africa. The Western Cape is home to approximately 4.7 million people – 10% of the South African population, and is composed of a 52% Coloured majority, a 24% White population and a 24% Black African population (Cummins 2002; Barron & Health Systems Trust 2006). The province represents the richest of the nine South African provinces and approximately 30% (R3.7 billion) of the provincial budget has been allocated to health care which has translated to a per capita expenditure on Primary Health Care of R306 per person, the highest in South Africa (Cummins 2002; Barron & Health Systems Trust 2006).

The Cape Town Metropolitan health district serves a concentrated geographic area which holds approximately 72% of the Western Cape population, an estimated 3.4 million people (Western Cape Department of Health 2007a). Approximately 73% of the population in the Cape Town Metropole is reliant on public health services where the remaining 27%, largely white, population is serviced by the private sector (MDHS Planning Task Team 2004; Cummins 2002). The Cape Town Metropolitan health district is divided into eight health sub-districts: Northern Panorama, Central, Southern, Klipfontein, Mitchell's Plain, Tygerberg, Khayelitsha and Helderberg which are illustrated in Figure 2.

This study focuses on the Mitchell's Plain sub district which, based on Censuses projections from 2001, holds a population of an estimated 460,686 people – 14% of the total population of the Cape Town Metropolitan health district (MDHS Planning Task Team 2004). The population of Mitchell's Plain is largely poor whereby 30% of households fell below the poverty line in 2003 and 41% lived in informal dwellings (MDHS Planning Task Team 2004). "Many households hav[e] no stable income and little social capital... [and] poverty results in the collapse of family life, escalating violence, substance abuse and an inability to escape the poverty trap" (MDHS Planning Task Team 2004, p. 12). This area of the Cape Metropole is notorious for high crime rates where homicide represents the leading cause of premature death, producing approximately 22% of all deaths in the sub-district in 2001 (MDHS Planning Task Team 2004).

Mitchell's Plain represents one of the provincial sub-districts with a relatively low HIV/AIDS prevalence rate, recorded to be 12.9% in 2004; HIV/AIDS was responsible for 15% of deaths in 2001 (Draper et al. 2007; MDHS Planning Task Team 2004; Shaikh et al. 2006). Overall HIV/AIDS prevalence in the Western Cape is below national averages (Draper et al. 2007; Shaikh et al. 2006). Tuberculosis rates in the Western Cape however are among the highest in the country; between 1997 and 2003, the Cape Town TB Control Report showed an increase of 66% in reported cases over the seven years, reflecting a growing population, migration, improved case detection and increased burden of disease, mainly in regions where HIV/AIDS is most prevalent (Draper et al. 2007; MDHS Planning Task Team 2004). Currently, the Western Cape's incidence rate of TB is 909 cases per 100 000 (Western Cape Department of Health 2011). 34% of the registered Provincial TB caseload is managed by twenty two high-burden facilities in the Cape Metropole district alone, two of which (Mzamomhle and Phumlani) exist in the Mitchell's Plain sub-district and have been represented by this study (Draper et al. 2007).

Primary Health Care (PHC) facility-based services (including TB services) are rendered through community health centres (CHCs) and local government clinics (Western Cape Department of Health 2011). These facilities serve as the entry points to the public health system and also act as referral units for those who need other levels of care (Western Cape Department of Health 2011). Services are provided primarily by clinical nurse practitioners (CNPs) who are supported by medical officers (Western Cape Department of Health 2011). There are fifteen clinics in the Mitchell's Plain sub-district which individually serve approximately 30,737 people (Western Cape Department of Health 2007a). In addition, there exist four CHCs which each serve a population of approximately 115,264 people (Western Cape Department of Health 2007a). The current population to facility ratio of 1:30,737 is substantially behind the national target of 1:10,000 (MDHS Planning Task Team 2004).

Data Analysis: Statistical Methods

For the purpose of this analysis, the exit interview content will be divided into three analytical domains, defined by the investigators as availability, affordability and acceptability. The availability domain will include physical access attributes including travel time to visit the facility, time taken to see the physician and/or nurse and mode of travel. The affordability domain will include financial access attributes such as total monthly expenditure on health care disaggregated by type of provider, total monthly expenditure as a percentage of household expenditure and how patients coped with health care costs. The acceptability domain will include cultural access attributes which will include variables related to stigma, respect as well as structural factors such as facility cleanliness.

Record review data will primarily be used for descriptive purposes; to identify patients who are not being treated for pulmonary TB (i.e. those being treated for extra-pulmonary TB) and; to distinguish the patient's prescribed drug regimen.

There have been a range of ways in which adherence has been defined in the research and policy context. As yet there exists no empirical definition for non-adherence which delineates the point at which a patient is said to be non-adherent. For the purposes of this investigation, the desired outcome

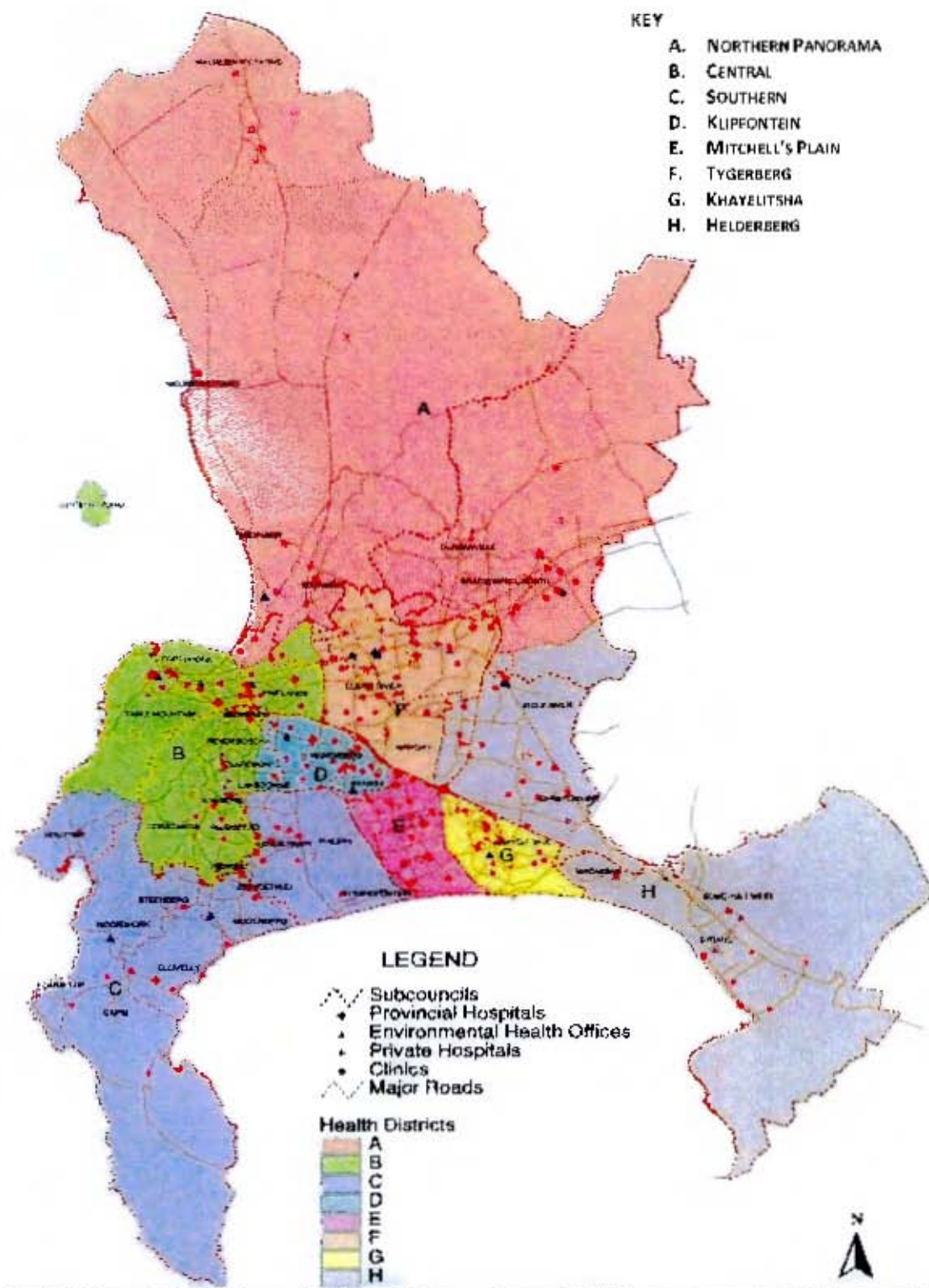


Figure 2: Map of the 8 Sub-districts of the Cape Town Metropole Health District (MDHS Planning Task Team 2004)

effects.

education and marital status will be entered into the regression in order to control for their respective performed where the outcome score for the access parameter is continuous. The effects of age, sex, used for access parameters which have binary outcome scores and simple regression analysis will be (i.e. to determine whether access varies by socio-economic status), logistic regression analysis will be in order to evaluate the independent effect of socio-economic status on the parameters of access,

Simple Linear Regression & Logistic Regression Analysis

statistically significant.

(for means) and Wilcoxon rank-sum tests (for medians). A *P*-value less than 0.05 is accepted as Fisher's exact test. Associations between continuous variables will be tested using the Student's *t* test associations between categorical variables will be compared using the Mantel-Haenszel chi-square or relationship between socio-economic status and the access dimensions of DOTS services. Bivariate and; the socio-demographic profile of respondents. Cross-tabulation will also be used to explore the between missing TB medication and; the availability, affordability and acceptability of DOTS services Bivariate associations (established through cross-tabulation) will be used to explain the relationships

Multiple Correspondence Analysis (MCA).

medication and patient groups who have not. Socio-economic status measures will be generated using describe the socio-demographic characteristics of patient groups who report having missed a dose of TB frequency distributions and univariate descriptive statistics will be used for preliminary analysis, to

Univariate & Bivariate Analysis

factors and not simply compliance with the medication regimen. alone. Readers must remain mindful that adherence is a dynamic process influenced by a range of 'adherence' or 'non-adherence' as adherence in this study focuses on missing doses of TB medications readers to be cautious when interpreting results, discussions and specific conclusions regarding unknown" (Van den Boogaard et al. 2011, p. 693). In light of this understanding, the authors urge the exact relationship between this risk increment and the duration of treatment until termination is Although the "premature termination of treatment increases the risk of treatment failure and relapse, report having ever missed a dose of TB medication will be used as a proxy for non-adherence. variable, patient adherence, will be measured using a process-oriented approach whereby patients who

ETHICAL CONSIDERATIONS

This study will involve the use of a secondary dataset which has already been coded and redacted to remove sensitive and confidential information and as a result no specific individual or household can be identified and the privacy of the participants has been upheld. Approval for the original study, of which this analysis is a subcomponent, was granted by Ethics committees at the University of Cape Town (see Appendix C), University of Witwatersrand and the University of KwaZulu-Natal and further permission to conduct research was granted by both provincial and local health authorities in South Africa.

WRITE UP & DISSEMINATION

As per the requirements of the Masters in Public Health (Health Economics specialization) program, outlined by the University of Cape Town; the research findings will be presented as a manuscript of a research article for submission to a suitable peer reviewed journal. In addition, a policy brief will be composed to provide a comprehensive and persuasive argument justifying the policy recommendations presented in the research article.

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PART B: LITERATURE REVIEW

INTRODUCTION

The following chapter presents a comprehensive review of literature which has been guided by the themes and objectives being explored in this study. Its purpose is to provide a rich theoretical and conceptual base of the ways in which the availability, affordability and acceptability of health services can impact equitable access to treatment; to examine the diverse methodologies which have been used to explore access and equity in health care provision particularly within low and middle income countries and; to provide an analysis of key empirical findings. The chapter first explores the concept of equity; the range of ways it has been defined, its importance in the context of health and health services and the interpretation of equity in the South African policy landscape. The chapter then provides a review of a number of different conceptual approaches to the relationship between access and equity. The final section of the chapter is guided by the conceptual framework of access put forth by Thiede et al (2007) and McIntyre et al (2009). This framework structures the discussion of a number of publications which have explored the barriers being faced in accessing health services across the dimensions of acceptability, affordability and availability. Published studies have been sourced from a variety of credible online databases which are widely used in public health research (including PubMed Ovid, Medline Ovid, Ebscohost and Google Scholar). An array of grey literature including technical reports and documents has also been integrated into the review, primarily sourced directly from the releasing government agency or organization (for example, the World Health Organization and the World Bank).

EQUITY IN HEALTH

Despite the widespread recognition of the importance of equity as a goal for health systems (with respect to health service delivery and financing) and the vast literature available on the subject, there has been little consensus on the definition of the term. There exists undisputed evidence that the health of individuals within and across nations varies significantly as a result of socio-economic disadvantage and geographic location (Whitehead 1992; Mackenbach & Kunst 1997). These variations are made particularly evident through the existence of weaker chances of survival, higher premature mortality rates, increased burdens and earlier onset of both chronic and communicable disease as well as increased disability among these underprivileged groups (Whitehead 1992; Mackenbach & Kunst

1997). Furthermore, evidence has revealed that individuals of lower socio-economic status use less health services, despite their needs, and spend a greater proportion of their income on seeking treatment which often forces them into poverty, a phenomenon known as the 'medical poverty trap' (Whitehead et al. 2001; Sauerborn et al. 1996; Asenso-Okyere & Dzator 1997).

Since the World Health Organization's Alma-Ata Declaration (1978) which promoted the need to improve the health profiles of those most in need through primary health care and preventative programs and the recognition that "fairness and social justice are valued by most societies" (Ong et al. 2009, p. 2), equity has been a central goal for global public health policy and practice. In 1986, the World Health Organization (WHO) expanded their views and defined equity in health as a situation in which "everyone should have a fair opportunity to attain their full health potential and...that no one should be disadvantaged from achieving this potential, if it can be avoided" (Whitehead 1992, p. 7; WHO 1986). This definition was further supported by Whitehead (1992) as she called attention to the important role that health services provide with respect to their abilities to improve health (Whitehead 1992; Krasnik 1996). In a similar light, Braveman & Gruskin (2003, p. 254) have defined equity in health as the "absence of systematic disparities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage/disadvantage"(Braveman & Gruskin 2003).

What seems most consistent from all literature is the notion that a health inequity exists if health inequalities are considered to be: (1) unfair; (2) unjust; (3) avoidable and; (4) unnecessary; and further, that tagging a difference in the health profile of one group as inequitable involves a moral and ethical judgment of the fairness of the causes of the inequalities (Whitehead 1992; Braveman & Gruskin 2003; Krasnik 1996).

As Braveman and Gruskin (2003, p. 254) highlight, "because social justice and fairness can be interpreted differently by different people in different settings, a definition [of equity in health] is needed that can be operationalised based on measurable criteria" (Braveman & Gruskin 2003). Despite the fact that equity and equality are two independent characteristics, equality is central in operationalizing equity (Braveman & Gruskin 2003). Absolute inequalities in the distribution of wealth and health across a population will affect human capital investments, which will therefore affect the capacity of individuals to engage in economic, social and political life. Ultimately, if we accept that

inequalities are a result of limited access to health services and unfair resource distribution processes as opposed to individual preferences, then they are indeed inequities (Braveman & Gruskin 2003; A. Sen 1973).

EQUITY IN THE SOUTH AFRICAN HEALTH SECTOR

Since the democratization of South Africa in 1994, the government has made significant progress in reversing the effects of the apartheid legacy which was characterized by severe inequality, health and development policy which was disproportionately focused on ensuring the survival of the white population's rule, as well as a fragmented, highly segregated and largely privatized health sector (McIntyre, Thiede, et al. 2006; Chetty 2007; Coovadia et al. 2009). The newly elected government, the African National Congress (ANC), immediately established their commitment to equity and social justice through the ANC National Health Plan and the White Paper for the Transformation of the National Health System for South Africa, which provided direction as to how the health sector would be transformed and later served as the foundation of the National Health Act, adopted in 2003 (Chetty 2007). The National Health Act (2003, preamble) explicitly focuses on the need to address "the socio-economic injustices, imbalances and inequities of health services of the past; the need to heal divisions of the past and to establish a society based on democratic values, social justice and fundamental human rights..." (Department of Health 2003, preamble; Chetty 2007, p. 4).

An abundance of structures and health policy initiatives have been formulated since 1994, however the South African health policy landscape can be broadly seen as targeted at three key areas:

- Equity in health service delivery and financing

- Redistributing public sector health care resources between and within provinces

- Increasing primary health care utilization levels for currently disadvantaged groups

- Addressing the public/private mix – facilitate making resources currently located in the private sector accessible to a broader section of the population, and/or redistributing resources from the private to the public sector

- Improving access to primary health care services

- Policies and programs targeting vulnerable groups and diseases of poverty

(Chetty 2007, p. 5; McIntyre, Gilson, et al. 2006)

Despite the newly adopted South African constitution which emphasized the “progressive realization of the right to health” (Coovadia et al. 2009, p. 824) and the strong commitment to transformation and equity of the health sector in and since 1994, health inequities have endured, exacerbated by failures of leadership, stewardship and management, the inability to provide a financing system that emphasizes income-related cross-subsidization across the health system as well as human resource limitations (Coovadia et al. 2009; McIntyre 2007).

South Africa represents a tiny percentage of countries whose life expectancy and childhood mortality rates have worsened since the Millennium Development Goals were established, further, “HIV and Tuberculosis epidemics, ...morbidity and mortality...from violence and injury, chronic diseases, mental health disorders, ...maternal [and] neonatal mortality” are among the notable reasons why South Africa has fallen short of health and health care expectations set at the time of liberation (Chopra et al. 2009, p. 1023). This trend can be seen most evidently by extreme differences in the prevalence and incidence of disease and rates of mortality between South Africa’s race groups: prevalence of HIV/AIDS among Indian South Africans, for example, falls between 0.6% and 1.9% whereas the prevalence of HIV/AIDS among Black South Africans has been found to be 13.3%; “in 2002, infant mortality [was] 7 per 1000 in the white population and 67 per 1000 in the black population, [further,] life expectancy for white adult women was 50% longer than it was for black women (Coovadia et al. 2009, p. 824).

Several reasons have been cited as to why the deep-seated commitment to equity in health and health services has not translated into positive gains for the South African population. The arrangement of public sector funding has seen a loss of power by the national government in affecting resource allocation decisions to the public health sector; funding has become largely dependent on “provincial priorities... [the] health sector is often forced to compete with other social demands such as education, housing and social development” (Chetty 2007, p. 31). In addition, inequities between the private and public sector continue to grow (McIntyre et al. 2008; Chetty 2007). Furthermore, the shortage of health workers and the emergence and rapid growth of HIV and Tuberculosis have limited the capacity for the South African health sector to respond effectively where poor management, stewardship and monitoring disable health policies aimed at responding to such trends, to be successfully implemented (McIntyre, Gilson, et al. 2006; McIntyre et al. 2008; Chetty 2007; Coovadia et al. 2009).

EQUITY IN HEALTH SERVICES

Health services are the means by which populations and individuals are granted the opportunity to achieve their full health potential and therefore serve a critical role in improving the health of both individuals and populations alike (Krasnik 1996; Whitehead 1992). As described by Aday and Andersen (1981), there are many influential forces that play a role in the health status of an individual; engaging in multiple-risk behaviours, genetic predispositions to ill-health, for example, are among these forces which cannot be controlled by the state (Aday & Andersen 1981). As a result, it is the responsibility of policy-makers and governments to create health systems which ensure that all people have the right to access health services to ensure they are granted their right to health (Aday & Andersen 1981).

As with many of the beliefs surrounding equity and its place in health and health services, there is no consensus among scholars as to the exact definition of 'equitable health services' or 'equity in health care'. Mooney (1983) summarizes two dominant views as: (a) equity in health services as occurring when a health system is resourced equally among all geographical areas (based on size of population) and; (b) equity in health services as only being attained when there is equality in the health profile of all individuals; when all individuals within a population have the same health status (Whitehead 1992; Mooney 1983). These positions have been criticized particularly because the former does not take into account the diverse needs for services among the different groups within their respective populations while the latter involves complex measures for 'health status' which are likely to be constructed differently across populations, leading to imprecision (Whitehead 1992; Makinen et al. 2000). Further, in practice, directing health policy at equalizing the health status of a population can mean that the distribution of health resources would in some cases be neither cost-effective nor efficient, since it can be quite costly to improve the health status of very sick people (Makinen et al. 2000).

Aday et al (1980) first proposed that "an equitable distribution of health care services is one in which illness is the major determinant of the allocation of resources (Krasnik 1996, p. 3; Aday, Andersen & Fleming 1980). In a later publication, they described equitable access to health services as a situation in which "services are distributed on the basis of people's need for them... [and] inequit[able access] is [identified when] services are distributed on the basis of demographic variables, such as race, family income, or place of residence, rather than need" (Aday & Andersen 1981, p. 6). Whitehead (1992, p. 8) refined this definition, stating that equity in health services is defined as:

1. Equal access to available care for equal need
2. Equal utilization for equal need
3. Equal quality of care for all

(Whitehead 1992)

Since then, utilization and access, two interrelated indicators have dominated health system equity research and policy. As defined by Mooney (1983, p. 179), “the difference between equity by access and by utilization lies in separating supply and demand (or need) issues...equality of access is about equal opportunity... whether or not the opportunity is exercised” (Mooney 1983). Of the two indicators, utilization, being more empirical in nature, has tended to be the focus of the majority of literature available on health service equity (Mooney 2009). This has hindered the usefulness of many of these studies, particularly in the research to policy context where recommendations are narrowly focused on health service delivery methods without attention given to “understanding the incidence, levels and types of use...and non-use of services...[to understand] how (and whether) the health care system interacts with individuals, households and communities” (McIntyre et al. 2009, p. 180; Mooney 2009). In later papers, Mooney et al (1991, 1992) defend the need to approach equity in health services by “equaliz[ing] access... [and] accept[ing the resultant] distribution of utilization and health” (Wagstaff & van Doorslaer 2000, p. 12; Mooney et al. 1991; Mooney et al. 1992).

What is made consistently clear from all discussions on equity, particularly within the context of health and health services is the fact that it can only be achieved if there exists a fair opportunity for all to achieve health. This understanding reflects the central role of access; if health services are the means by which populations and individuals are granted the opportunity to achieve their full health potential then it undoubtedly follows that equity in health is dependent on the equity which exists in access to health services (Krasnik 1996; Whitehead 1992). Therefore, fundamental to any discussion of equity requires a deeper understanding of the concept of access.

ACCESS TO HEALTH SERVICES

Despite a considerable body of research dedicated to conceptualizing access to health services, there has long-existed a cloud of ambiguity surrounding a universally-acceptable, empirical definition of the

term, particularly when being operationalized to evaluate health systems in low- and middle-income countries (LMICs) (Thiede et al. 2007; Oliver & Mossialos 2004; Gulliford 2009; Aday & Andersen 1974). As explained by Thiede et al (2007, p. 105), "...if the access concept is not well understood, comprehensive evidence on what should be done to promote equitable health systems cannot be gathered", especially in the research-to-policy context (Thiede et al. 2007). Furthermore, the inconsistency of notions of 'equitable access' render policy-makers worldwide "without a reference point against which to judge the consistency of their healthcare policies" (Oliver & Mossialos 2004, p. 655), which has, in some cases, seen health policies aimed at improving access indirectly worsen the inequity of health service access (Oliver & Mossialos 2004). The early 21st century has seen a growing acceptance of the important role of individual autonomy and the need to balance traditional notions of 'top-down' and 'bottom-up' health policy formulation and implementation (Gulliford 2009). This awareness has given rise to an evolution in the ways in which access and equity have been conventionally defined (Gulliford 2009).

Traditionally, there have been four schools of thought with respect to access to health services, each differentiated from the other by placing varying levels of importance (or in some cases, unimportance) on those issues concerned with supply and those concerned with demand (or need). When access is seen as the consequence of supply-side dimensions alone, studies often narrowly focus on accessibility to health services with respect to their location and density; this type of approach often sees access in terms of 'spatial accessibility' and has been criticized for being highly simplified in nature (McIntyre et al. 2009). Even where a health facility is identified as providing a particular service within an area for which there is a need, many individuals may be unaware of their availability and efficacy and thus there is no guarantee that those in need have the opportunity to use these services (McIntyre et al. 2009; Goddard & Smith 2001).

A second approach to health service access is dominated by studies which place greater importance on demand-side considerations. In these cases, affordability of services is seen as the sole proxy of access (McIntyre et al. 2009). Those that follow this approach tend to look at the prices of the services themselves and the individual's ability to pay for these services based on their insurance coverage, income and/or eligibility for government-funded services (Penchansky & Thomas 1981). Critiques of this view emphasize that the impact of the price of services can jeopardize access for some while access to health services for others (typically those belonging to a different socio-economic group) can remain

unchanged (Gulliford et al. 2002). In this way, "the impact depends on the magnitude of the costs and on the user's willingness and ability to pay; equal costs do not necessarily give equal access" (Gulliford et al. 2002, p. 187)

A third approach and one of the most widely referenced views of access to health care in the past decade has seen access being expressed in terms of use of services (Donabedian 1972; Andersen 1995; McIntyre et al. 2009; Ricketts & Goldsmith 2005; Penchansky & Thomas 1981). Aptly summarized by Donabedian (1972), many who have inherited this view believe "the proof of access is use of service, not simply the presence of a facility" (Gulliford et al. 2002, p. 187; Donabedian 1972). Service use is analysed both in terms of actual use of services (absolute terms) and in terms of the differential use of health services across groups and individuals with diverse needs (relative terms) (McIntyre et al. 2009). As pioneers of this approach, Andersen, Aday and Newman (1974; 1980; 1981; 1995) devised a framework which has been highly influential in health-policy formulation (Aday & Andersen 1974; Aday & Andersen 1981; Andersen 1995; Ricketts & Goldsmith 2005; Aday, Andersen, Fleming 1980). Despite the evolution of their framework over time, their approach essentially associates use of services with different classes of access; these classes include potential, realized, effective and efficient access (Andersen 1995; McIntyre et al. 2009; Ricketts & Goldsmith 2005). Where access to a particular service is deemed the same across individuals and groups, and where absolute and/or relative measures of utilization are seen to be different, the framework uses "*predisposing [components]* (generally characteristics of individuals), *enabling [components]* (system or structural characteristics)" (Ricketts & Goldsmith 2005, p. 274) as well as biological need to explain these differences (Penchansky & Thomas 1981; Andersen 1995; McIntyre et al. 2009).

Despite extensive explanations of the differences between classes of access as defined by Andersen (1995), confusion exists around the distinctness of each class (Andersen 1995; Gulliford et al. 2002). Nonetheless, it is important to mention that this framework introduces the notion of potential access (which allows for realized access) to health services as being completely dependent on enabling factors which are concerned with the structure and processes of health systems (Andersen 1995). As a result, "early users of this access concept attempted to create global indicators of access that focused on process[es];... the travel time to care; ability to get an appointment in a reasonable time; and in office waiting time... measures [which] are regularly included in national surveys" (Ricketts & Goldsmith 2005, p. 275).

Undoubtedly, this framework has been the basis of the majority of academic efforts concerned with understanding and measuring access to health services and its implications for equity, over the past decade. As a result, the value of the contributions of Andersen, Aday and Newman (1974; 1981; 1995) cannot be ignored (Aday & Andersen 1974; Aday & Andersen 1981; Andersen 1995). Likewise, their limitations cannot go unnoticed. As explained by McIntyre et al (2009, p. 182), this method sees “an individual who did not use services, or used services differently from others with the same needs [as having] different access to care” (McIntyre et al. 2009). This cannot hold true where it is impossible to assume that all individuals share the same “beliefs, values, and attitudes towards illness and health care” (McIntyre et al. 2009, p. 182-183). Another limitation of this method is its inability to thoroughly consider equity in access to health services (Daniels 1982). Their method does not show how process factors (such as waiting time or fees associated with treatment) can represent a greater burden to some, particularly where utilization rates are constant (Daniels 1982). Further, those that seek to use this method to evaluate access to health services are required to possess data related to the use and non-use of services, typically only available through household surveys.

An alternative means of looking at the access concept was developed by Penchansky (1981) in response to a need to “define and measure...phenomena [beyond the ability to use, willingness to use or actual health service use] which significantly influence the use of health care services ...to obtain desired intermediate or final outcomes” for health system strengthening (Penchansky & Thomas 1981, p. 127-128). In an attempt to fill this void, Penchansky (1981, p. 128-129) described the heart of the concept of health service access as the degree of fit between traits of the health system and characteristics and expectations of the individuals it serves based on five measurable criteria:

1. Availability (volume of physicians and other health care services);
2. Accessibility (spatial relationship between the providers and users of care);
3. Accommodation (content and organization of the health system and the ease with which people can use care);
4. Affordability (both the financial ability-to-pay and the user's perception of value);
5. Acceptability (the attitudes of users toward the providers, and vice versa).

(Penchansky & Thomas 1981, p. 128-129; Ricketts & Goldsmith 2005, p. 275)

As explained by McIntyre et al (2009, p. 181), Penchansky's contributions were particularly significant as they revealed access as a "communicative interaction" (McIntyre et al. 2009) between the health care system and the individuals it serves (McIntyre et al. 2009). In this way, it becomes clear that "what constitutes compatibility between one individual and the system (e.g., the availability of female physicians) may represent incompatibility for another" (McIntyre et al. 2009, p. 181).

What can be seen from the majority of theoretical literature on the concept of access is the fact that the concept itself is constructed of a wide array of dimensions, many of which are closely interrelated, presenting both at the supply and demand side of health service access.

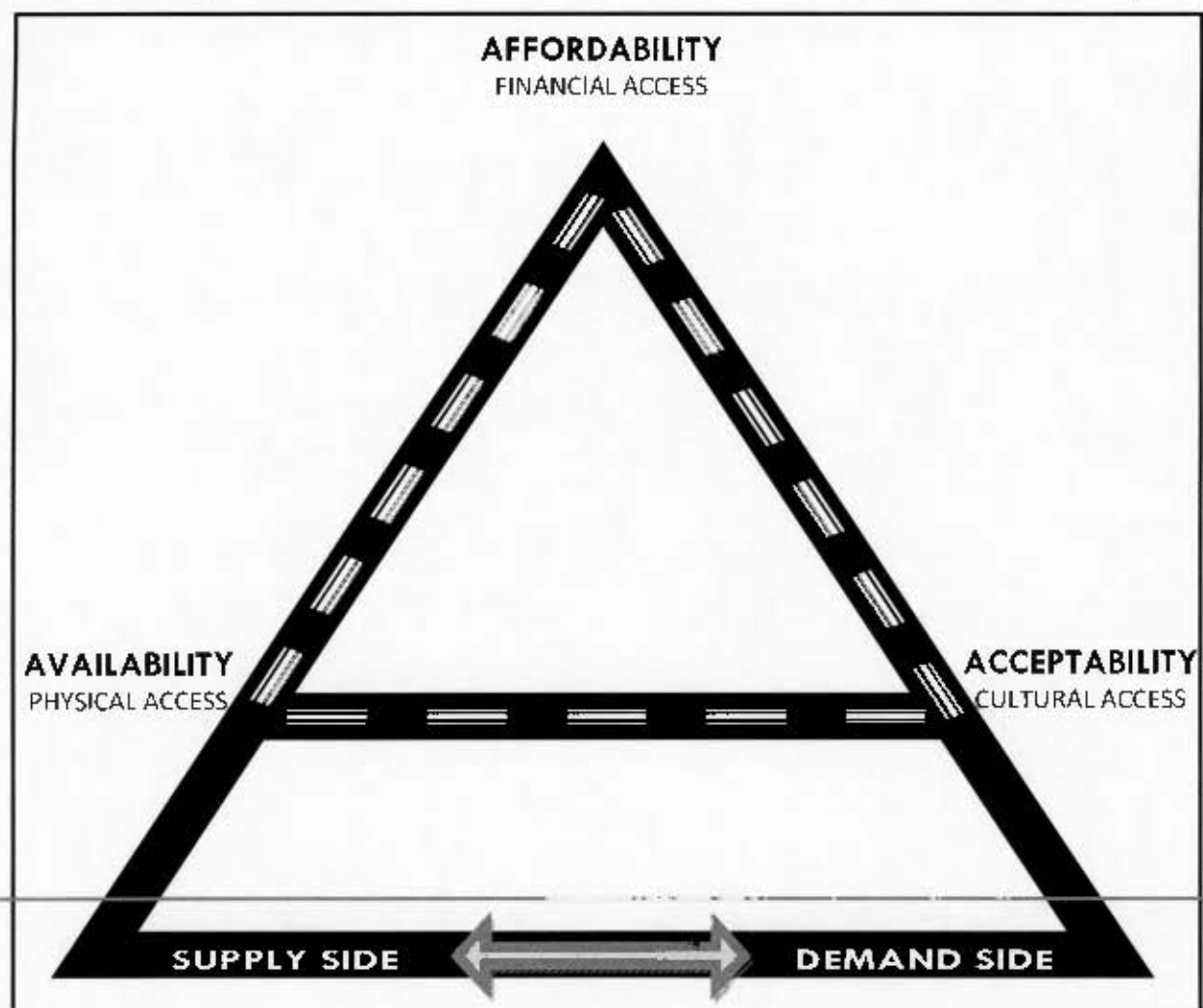
THREE DIMENSIONS OF ACCESS

The most recent contributions to the study of access, particularly in its application to low and middle income countries has been developed by Thiede et al (2007) and further described by McIntyre et al (2009) (Thiede et al. 2007; McIntyre et al. 2009). Their framework first explores the importance of understanding access as a unique experience; the empowerment of individuals to use and benefit from health services (McIntyre et al. 2009). By viewing access as empowerment, a balance is created between the role of health system financing and delivery and between the ways in which individuals gain from the interaction with their health system (Thiede et al. 2007; McIntyre et al. 2009). Thus, they state that in order for health services to be equitably accessible to all individuals, it is the responsibility of policy-makers to go further than ensuring they are available or present within a given community; their responsibility extends to ensure that efforts are made to empower individuals to choose to use services if and when they are needed (Thiede et al. 2007; McIntyre et al. 2009). By this definition, access is not equivalent to use; "empowerment offers individuals the opportunity to realize their preferred choices, which may encompass non-use as well as use of health services... [therefore] if the potential to use a service exists, then access is present even when an individual makes the choice not to use care" (Gulliford 2009, p. 224).

As mentioned, traditional schools of thought regarding access can be differentiated from one another as they place varying levels of importance (or in some cases, unimportance) on those issues concerned with supply and those concerned with demand (or need). The framework proposed by McIntyre et al

(2009) is unique as it considers the supply and demand side forces concurrently and in relation to one another (Thiede et al. 2007; McIntyre et al. 2009). Their framework asserts that access to health services can only be understood when characteristics of the individuals and characteristics of the health system are considered together and relative to one another as they are constantly engaging in a dynamic process of interaction (McIntyre et al. 2009). The degree of access to a particular health service is therefore governed by the relative fit between the system and the individuals it serves across all individual and system factors which have the potential to affect the freedom to use health care. This notion of a 'degree of fit' was initially proposed by Donabedian (1972) and Penchansky (1977), however was never regarded as the core of the access concept until now (Thiede et al. 2007; Donabedian 1972; Penchansky & Thomas 1981).

Undoubtedly, the task of establishing a general consensus of *every* factor that has the potential to affect an individual's freedom to use health care on both the supply and demand sides presents a daunting and perhaps unachievable task. As a result, Thiede et al (2007) and McIntyre et al (2009) provide a broad conceptual framework which allows for the empirical examination of access by grouping factors into three key dimensions: affordability, acceptability and availability (McIntyre et al. 2009; Thiede et al. 2007). In this way, the authors assert that "access...to use health care services will only be



achievable if all dimensions of access are addressed and both the health care system [(supply-side)] and individual [(demand)] perspectives are taken into account" (McIntyre et al. 2009, p. 190; Thiede et al. 2007). This conceptual framework, referred to as "The A-Frame" (McIntyre et al. 2009, p. 180; Thiede et al. 2007, p.110) is illustrated in Figure 3. As shown in the diagram, a fundamental part of the framework is the understanding that while each dimension is concerned with its own set of issues: affordability being primarily concerned with factors related to financial access; availability being concerned primarily with those factors which are related to physical access and; acceptability being concerned with those factors are related to cultural access; that the dimensions are interrelated (McIntyre et al. 2009; Thiede et al. 2007). As a result, interventions aimed at improving access cannot be carried out unless the interactions between the health system and the individuals it serves across these dimensions are considered (McIntyre et al. 2009; Thiede et al. 2007).

DIMENSIONS OF ACCESS		
AVAILABILITY	AFFORDABILITY	ACCEPTABILITY
Mode & Cost Of Transport	Total Expenditure (Direct & Indirect) On Health Care Including: Expenditure To Reach Facility Expenditure On Self Care Expenditure On Other Providers Lost Wages As A Result Of Facility Visit	Perceptions Of Staff Attitudes, Facility Cleanliness, Length Of Queues, And Community Judgment (As A Proxy For Stigma), Confidentiality And Privacy.
Travel Time To Facility	Healthcare Costs As A Proportion Of Household Expenditure	Expectations Of Patients To Providers Including Adherence To Prescribed Treatment.
Waiting Time At Facility	Ability To Borrow Money To Pay For Healthcare Expenses	Perceptions Of The Effectiveness Of Treatment
Availability Of Government 'Disability' Grants	Receipt Of Government 'Disability' Grants	
Range Of Services Relative To Need	Perceived Ease/Difficulty Of Incurring Expenses.	
Location Of Services	Individuals Perception Of Value For Money	
Hours Of Service Of Health Facility	Unofficial or 'under-the-table' fees	

Table 2: Dimensions of Access (adapted from McIntyre et al. 2009; Thiede et al. 2007).

In practice, the dimensions of acceptability, affordability and availability are most often captured by several fundamental variables which are summarized in Table 2 and further clarified in the following sections.

ACCEPTABILITY OF HEALTH SERVICES & IMPLICATIONS FOR EQUITABLE ACCESS

Of the three dimensions, acceptability has received the least attention with regards to both empirical and conceptual literature however, systematic differences in health care utilization can be seen to be closely associated with acceptability barriers among high-, middle- and low-income countries alike which is indicative of its importance, particularly with regards to discussions on health care equity policy (Gilson 2007; McIntyre et al. 2009). Acceptability refers to the ways in which individuals and communities seeking care perceive health service provision (Thiede et al. 2007). This dimension is affected by culture, language, ethnicity and gender which collectively shape the attitudes of patients and providers within the health service delivery environment and tend to be among the primary determinants of the sensitivity of a given health system to the beliefs and expectations of those it serves (and vice versa) (McIntyre et al. 2009; Thiede et al. 2007). As summarized by McIntyre et al, 2009: "acceptability is concerned with the fit between provider and patient attitudes towards and expectations of each other" (McIntyre et al. 2009, p. 187). Gilson (2007, p. 124) further adds to this definition by describing acceptability as the "social and cultural distance between health care systems and their users" (Gilson 2007) which is hinged on the level of trust which exists within the relationship between the providers and the patient. In the context of access, these factors are of most value in the ways in which they influence an individual's ability or freedom to receive care (McIntyre et al. 2009).

To understand acceptability, we can systematically analyze its influence on an individual's ability or freedom to use health care by examining two key elements as defined by Gilson (2007): (a) the fit between lay and professional health beliefs and; (b) patient-provider engagement and dialogue.

Degree of Fit between Lay and Professional Health Beliefs

Lay health beliefs encompass the ways in which individuals within a given community understand their symptoms, disease and the effectiveness of treatment alternatives (Gilson, 2007). This also includes how patients rate the technical competence of health providers and pharmaceutical interventions (Gilson 2007; McIntyre et al. 2009). Globally, health care systems have long been grounded in the

biomedical model of medicine which, at its core, views disease in terms of pathology, biochemistry and physiology. This has created a situation where the social determinants of disease (and health) are often neglected causing a pervasive difference in the health beliefs of health care providers and the individuals they serve (Gilson 2007). Such a situation has led to a general mistrust in health care among many lay-populations which has a well-documented effect on how and if individuals seek allopathic treatment (Gilson 2007).

In a study of the acceptability of an HIV vaccine among young adults in South Africa, Sayles et al (2010) used a series of focus group discussions to determine key motivational factors and barriers to the potential uptake of the intervention (Sayles et al. 2010). Their findings illustrate the negative effect that disparities in health beliefs can have on an individual's treatment seeking behaviour. The authors findings reveal a mistrust in both the government and the scientific community as all participants believed that "the risks and toxicities associated with an HIV vaccine would not be fully disclosed [to them]" (Sayles et al. 2010, p. 198) and further believed that health providers would paint a false picture of the efficacy of the vaccine (Sayles et al. 2010). Another key finding demonstrates a general mistrust in western medicine relative to traditional African medicine (Sayles et al. 2010). Five of the six focus group discussions that were conducted revealed that individuals would be reluctant to receive the HIV vaccine because it was not aligned with their traditional beliefs of healing (Sayles et al. 2010). Furthermore, 80% of the participants believed that they were not personally vulnerable to HIV, which is of particular concern as perceived vulnerability is often observed as a key determinant of preventative action (Sayles et al. 2010).

In another study, Munro et al (2007) conducted a systematic review of qualitative research on patient adherence to TB treatment (Munro et al. 2007). Their findings showed that individuals refused to believe and accept that they had TB due to their doubts over the validity of the diagnostic methods and confidence in the medical system (Munro et al. 2007). In many instances, this denial resulted in poor treatment adherence whereby treatment was ceased once symptoms had disappeared (Munro et al. 2007). Further, Munro et al (2007) illustrate that in many cases, TB treatment was not initiated at all particularly due to false beliefs regarding the negative side effects of treatment as well as the inefficacy of treatment alternatives (Munro et al. 2007). In much the same way, Chuma et al (2010, p. 10) revealed that "the community's poor perceptions of quality of care, lack of trust in health providers"

(Chuma et al. 2010) and their perception of the effectiveness of government-issued drugs were among the most prominent barriers of access to malaria treatment in Kenya (Chuma et al. 2010).

Engagement and Dialogue between Patient and Provider

The nature of the interaction between the patient and the provider has the potential to dissuade individuals from seeking health services particularly through provider attitudes towards patients, discrimination as well as issues of confidentiality which have a seemingly large effect on the level of trust shared between patient and provider (Gilson 2007). The relationship between provider and patient inherently involves a complex power dynamic whereby “providers [are able to] exercise their power through their communication practices” (Gilson 2007, p. 130) and their commitment to maintaining confidentiality and refraining from making assumptions about particular groups and individuals which may result in differential treatment of certain individuals and groups (Gilson 2007). A qualitative study of clinical care for HIV patients in rural Zimbabwe uncovered how control over patient movements in health facility spaces reinforces power inequalities between patients and health workers (Campbell et al. 2011). Patients were exposed to erratic demands by facility staff to form lines or assemble in a particular manner which they found to be extremely disempowering (Campbell et al. 2011). Furthermore, providers may subconsciously treat those that they believe to be ‘blamed’ for their illness more harshly than others (McIntyre et al. 2009). Bakeera et al (2009) found that service acceptability was primarily determined by health worker attitudes (Bakeera et al. 2009). Participants observed health providers treating pregnant women who appeared to be older in an inhumane manner simply due to their age; participants further added that these practices brought about “fear and scepticism in using the service” (Bakeera et al. 2009, p. 6).

Much of the literature on acceptability makes reference to the effect of this interaction. In a 2004 discussion paper by the World Bank on barriers to health service access, differences in the social status between a health provider and the patient was deemed a significant determinant of utilization of health services (Ensor & Cooper 2004). The authors explain that many patients often feel inferior to their health providers and convey a perceived lack of ability to communicate with their providers effectively in a wide array of contexts (Ensor & Cooper 2004). In Malawi, O’Gorman et al (2010) illustrated how the negative and threatening attitudes of health workers was a key barrier to access of Nevirapine, a method of prevention of mother to child transmission (PMTCT) of HIV/AIDS (O’Gorman et al. 2010). Through a series of focus group discussions and in-depth interviews, participants shared that health

providers were harsh and threatening, creating a widespread belief that they had no respect for the patients (O’Gorman et al. 2010). The following transcript from an interview with an Antenatal participant aptly summarizes their sentiments:

"[The health workers] shout, insult women even when the time has come for the women to deliver. They even leave you to deliver on your own while they are shouting bad words at you. There are times when you try to call them for help, they do not come...it can be when the mother delivered at home, she can have fear to go to the hospital [for nevirapine syrup], because most of us fear to be shouted at by doctors because of delivering at home"

(O’Gorman et al. 2010, p. 4)

In the case of TB, adherence to treatment has also been shown to be affected by the nature of the interaction between the patient and the provider. Providers were seen to harshly reprimand patients who had missed scheduled appointments; patients were threatened and humiliated by enraged facility staff, the combination of which resulted in non-adherence to TB treatment (Munro et al. 2007; Sagbakken et al. 2008).

Demand-side factors also play an important role in the interaction between patient and provider. Individual characteristics of the patients themselves may make them more willing to disclose information, having more confidence in providers which share their ethnicity, language or gender (McIntyre et al, 2009; Gilson et al, 2007). A key demand-side factor which presents itself in much of the literature is stigma. As described by Gebremariam et al (2010, p. 6), "fear of stigma lead[s] to...patients not disclosing their illnesses [to providers] but also [leads to] TB treatment in their catchments [becoming] difficult...for fear of being identified by neighbours" (Gebremariam et al. 2010). Similarly, in a study of access barriers to health care for the chronically ill in South Africa, Goudge et al (2009) found that over a third of respondents with a chronic illness were unable to report their diagnosis which the authors owe to a lack of effort on behalf of facility staff to ensure that the patients understand and absorb the information they provide, as well as the fact that the stigma attached to their diagnosis does not harbour clear communication between patient and provider (Goudge et al. 2009).

The benefits of productive interactions between the patient and provider extend beyond the fact that patients are enabled and empowered to seek and adhere to treatment. Where patients understand their diagnosis and trust in both the integrity of health workers and the efficacy of treatment, they are

able to make a well-defended case for financial assistance and furthermore are able to serve as a resource to their communities and to the health system, potentially empowering others to seek treatment (Goudge et al. 2009).

AFFORDABILITY OF HEALTH SERVICES & IMPLICATIONS FOR EQUITABLE ACCESS

The affordability of health services has been the most frequently discussed dimension of access in light of the debilitating costs of illness, particularly for populations existing within low and middle income countries (LMICs) (McIntyre, Thiede, et al. 2006; Thiede et al. 2007). The concept of affordability broadly describes an individual's financial access to health services by exploring the relationship between the package of costs of seeking care (borne by the individual and their household) and their ability-to-pay for these services, reflected most often by their socio-economic status (Thiede et al. 2007). The concept further encompasses the impact of these costs on the livelihood of the individual seeking care and their household (McIntyre et al. 2009). In recent years, the notion of financial risk protection has been at the forefront of the global health policy agenda in response to an abundance of literature which reflects the dynamic, multifaceted ways in which the affordability of health care has exacerbated inequity in health and access to health care among populations globally (McIntyre, Thiede, et al. 2006; Thiede et al. 2007).

Economic Costs of Illness: Direct & Indirect Costs

The economic cost of illness encompasses both direct and indirect costs (McIntyre et al. 2009; Thiede et al. 2007). Direct, out-of-pocket, costs refer to the financial costs of care, typically inclusive of: official consultation fees (or, if insured, co-payments); unofficial consultation fees, also referred to as 'under-the-counter fees; fees attached to diagnostic tests, scans or procedures; fees for prescription and non-prescription medications; fees associated with hospitalization (e.g. pre-admission deposits, ward fees, theatre fees) and; other items which necessitate direct payment such as transportation, extraordinary dietary requirements as a result of treatment or while seeking care and child-care costs (McIntyre et al. 2009; Thiede et al. 2007).

Indirect costs typically measure productive time losses such as lost income while travelling and receiving care, for the patient and those accompanying them (McIntyre et al. 2009; Thiede et al. 2007; McIntyre, Thiede, et al. 2006). Methodological issues with calculating the economic cost of illness and ultimately the affordability of accessing care generally stem from the fact that indirect costs are often

more difficult to calculate where “differences arise according to whether total productivity loss is estimated as the number of days off work due to illness only or whether the years of productive life lost due to premature death are also included” (McIntyre, Thiede, et al. 2006, p. 860). Further challenges may arise through the different ways these measures are transformed into monetary values, whether average wage rates or actual income losses are applied to productive time losses and further and how studies quantify time losses for those who are not employed in the formal sector (McIntyre, Thiede, et al. 2006). The following discussions reflect the considerable burden that indirect costs can represent and the central role they serve in an individual’s ability to access treatment (McIntyre, Thiede, et al. 2006).

While illness occurs in individuals, its costs do not fall on ill individuals alone thus it is important to include the household as a unit of analysis for treatment seeking behaviour, given that the “large majority of time and financial costs of illness [are] borne by healthy household members” (Sauerborn et al. 1996, p. 291). There has been significant attention paid to the costs of illness at a household level which has been triggered by the “growing empirical evidence that user fees at public facilities, and a growing reliance on private for-profit providers for whose services there are frequently direct payments, constitute a major financial burden on households” (McIntyre, Thiede, et al. 2006, p. 858).

Approaches for estimating direct and indirect costs of illness vary widely by health condition as well as the nature and availability of data (Bloom et al, 2011; (McIntyre, Thiede, et al. 2006)). Though national household surveys are often the source of data, comparisons of costs of illness across countries can sometimes be limited due to the fact that surveys differ by sample size, recall period, geographical area and statistical power (Makinen et al. 2000). In the sphere of public health and health economics, two key indicators have been consistently used to describe the economic cost of illness: (1) Health care expenditure as a proportion of household income (direct cost burden) and; (2) Production and income loss caused by illness as a proportion of ‘normal’ income (indirect cost burden) (Russell 2005). The former considers the opportunity cost of making health care payments and the related consequences for households while the latter considers indirect income losses (Russell 2005).

In 1993, Leighton & Foster (1993) found that the total annual health costs of malaria in Kenya could range between 4% and 9% of annual household income while in Nigeria these costs could range between 4% and 13% (Leighton & Foster 1993). The authors focused on the direct costs of out-patient

treatment and the cost of productive time losses, considering both lost workdays due to malaria and lost productivity while working during illness (Leighton & Foster 1993). Notable differences among rural and urban populations, male and female workers as well as differences among populations belonging to the formal, informal, agricultural and service sectors were also considered (Leighton & Foster 1993).

Leighton & Foster (1993, p. 76) describe how lost income and costs of health care affect households differently according to their field of employment, in particular noting that the burden is considerably larger for those who belong to the lowest income groups; rural, farming households, for example, are most affected in Kenya while "lower-income informal sector households suffer the highest burden in Nigeria" (Leighton & Foster 1993). According to their findings, these households stand to lose a far greater share of their income to malaria than their better off counterparts; 2-3.5 times greater proportion of annual household income in Kenya, and potentially 2.5-to-4 times greater proportion in Nigeria (Leighton & Foster 1993).

TUBERCULOSIS: SUMMARY OF DIRECT, INDIRECT & TOTAL HOUSEHOLD COSTS					
COUNTRY	DIRECT COSTS	INDIRECT COSTS	TOTAL COSTS	SAMPLE SIZE	REFERENCE
	US \$ (% OF ANNUAL HOUSEHOLD INCOME)				
Thailand (urban/rural)	\$131 (8.6%)	\$53 (2.3%)	\$184 (10.9%)	673	Kamolratanakul et al, 1999
India (urban/rural)	\$60 (13%)	\$117 (26%)	\$177 (40%)	304	Rajeswari et al, 1999
Zambia (urban/rural)	\$49 (8.3%)	\$28 (4.8%)	\$77 (13.1%)	202	Neecham et al, 1998
Tanzania (urban)	\$52 (9.3%)	\$447 (80%)	\$499 (89.3%)	191	Wyss et al, 2001

*All prices reflected at the 1999 US\$; Costs as a % of income are estimates based on the studies own estimates of income
 Table 3: Economic Costs of TB (Adapted from (Russell 2004))

In a similar way, Russell (2004) conducted a critical review of empirical data to determine the economic costs and consequences of HIV/AIDS, malaria and TB in developing countries, illustrating that resource-poor settings experience highly regressive cost burdens for households facing illness (Russell 2004). Findings related to the economic costs of TB are presented in Table 3.

Of the settings being evaluated, the total costs to households ranged between approximately US\$75 to well over US\$450, imposing cost burdens of 13% and 90% of annual household income, respectively, in

already impoverished settings (Russell 2004). Russell (2004) explains how indirect costs of TB generally impose higher cost burdens (relative to many other diseases) because of the lengthy duration of illness associated with the disease, delays associated with receiving a concrete diagnosis as well as its dominance among individuals who are economically active (Russell 2004). The author further suggests that the impoverishing effect of these costs on households is a common reason why many avoid treatment; in Tanzania, 90% of the annual household income is dedicated to treating TB, likely forcing households to exhaust resources allocated to their basic needs in order to ensure their ill family member is tended to (to be further discussed in the following sections) (Russell 2004). The magnitude of indirect costs has also been highlighted by a number of other studies, many of which have found indirect costs to far exceed direct costs (Koopmanschap & Rutten 1994; McIntyre, Thiede, et al. 2006). Indirect cost estimates for some low and middle-income countries are 2 to 3.6 times greater than direct costs (Asenso-Okyere & Dzator 1997; Attanayake et al. 2000; Ettling & Shepard 1991; Sauerborn et al. 1996; McIntyre, Thiede, et al. 2006).

Studies on the economic cost of illness have also pointed policy-makers toward the importance of reducing the cost of drugs available to treat illness. Medications have been seen to represent over 60% of total direct costs for treatment of malaria and lymphatic filariasis in Ghana and India, respectively and over 30% of direct costs across all illnesses in Sri Lanka (Asenso-Okyere & Dzator 1997; Babu et al. 2002; Russell 2001; McIntyre, Thiede, et al. 2006). Furthermore, transport as well as the need to provide accommodations and nutritious food for patients and their caregivers during travel to a health care facility can significantly intensify costs to the household, particularly in rural settings where health care providers may be situated a substantial distance away (Attanayake et al. 2000; Nahar & Costello 1998; Babu et al. 2002; McIntyre, Thiede, et al. 2006). TB treatment, for example, requires the intake of nutritious foods that can also place huge costs on the household and though these costs are often not included in estimations of treatment costs, they represent a noteworthy expense for poor households; “foods that are not usually part of patients’ diets (meat, eggs, vegetables, oranges) can account for up to 44% of a patients’ or households’ income” (Russell 2004, p. 149). The burden of food and accommodations, and transport for ill-family members and their caregivers has, in other studies, been approximated to represent 20% of direct costs in some contexts (Attanayake et al. 2000; Nahar & Costello 1998; Babu et al. 2002; McIntyre, Thiede, et al. 2006).

Ability-To-Pay & Coping Mechanisms

Morbidity and mortality are often measured in order to estimate the burden of disease in populations, however, ill-health imposes a range of consequences on the welfare of the individual and household (WHO Department of Health Systems Financing 2009). "‘Health shocks’ or the unexpected increases in health expenditure, reduced functional capacity and lost income or productivity are often a primary risk factor for impoverishment" (WHO Department of Health Systems Financing 2009, p. 8); households risk worsening health by adapting their use of healthcare to evade costs they cannot face, or employing financial strategies which compromise their livelihoods (Goudge et al. 2007). It has been widely accepted that where the total economic costs of illness represents 10% or more of a household’s income (as in the majority of cases described above), households are at risk of impoverishment; a lesser proportion is likely to be catastrophic for poorer households (Ranson 2002; Prescott 1999; McIntyre, Thiede, et al. 2006). As a result, ability-to-pay is the second key component of the concept of affordability and relates to the ways in which individuals and households manage and respond to the economic costs of illness.

While households in different countries and contexts are likely to respond differently to ‘health shocks’ (as defined by the WHO (2009)), McIntyre et al (2006) have established a simplified flow-chart of the key issues relating to the economic consequences of illness (depicted in Figure 4)(WHO Department of Health Systems Financing 2009; Leive & Xu 2008; McIntyre, Thiede, et al. 2006). While this framework is extremely useful in guiding those who seek to understand the experiences of households, it is important to recognize that those who are too poor to access and use health services are not captured. Formal health insurance and credit programs are rare in many low and middle income countries, as a result, households will exhaust their savings, “sell assets, borrow money from friends and family or take out a loan using collateral” (Leive & Xu 2008, p. 849) to cope with medical bills (Leive & Xu 2008). If illness occurs in a head of household or a member who is depended on for income, households may be forced to make decisions regarding labour allocation to make up for lost income or productivity (Leive & Xu 2008). Ability-to-pay is a combined measure of several factors including: how individuals benefit from public funding (national insurance schemes, disability grants); the value and schedule of income within the household (and the resultant capacity of a household to make payments for health care); the ease at which additional sources of funding can be mobilized which is dependent on the amount and nature of household assets (and the ease at which they can be converted for cash) as well as confidence in community members to provide financial assistance (through gifts and loans) and; a household’s capacity to face indirect costs (such as the level of support from employers through sick leave policies

and a household's ability to rely on other family or community members to provide child care) (McIntyre et al. 2009; Thiede et al. 2007).

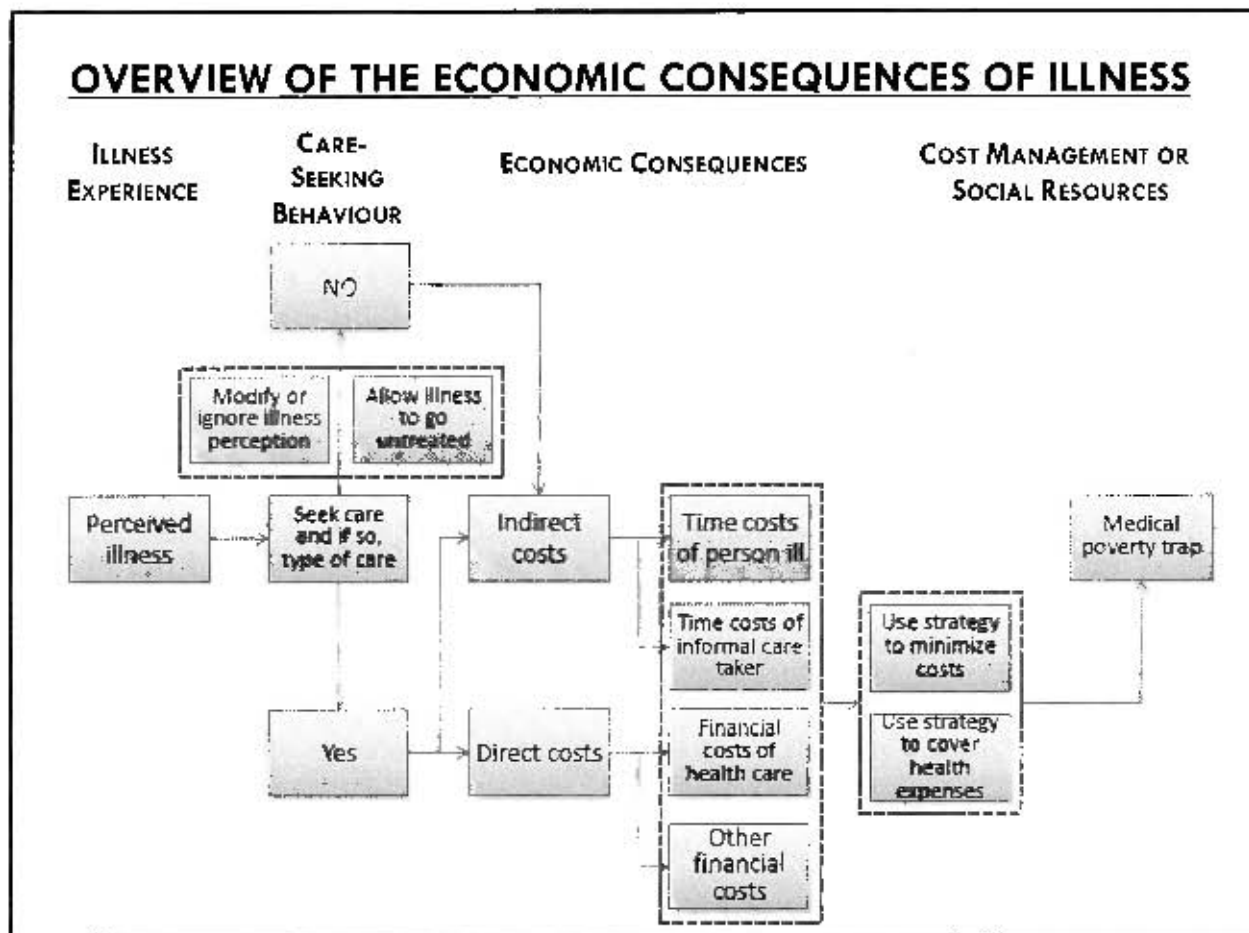


Figure 4: Simplified Flow Chart of Key Issues Relating to the Economic Consequences of Illness (Adapted from (McIntyre, Thiede, et al. 2006))

Using a series of logit regressions, Leive & Xu (2008) explored household coping behaviours in fifteen African countries to the medical payment of treatment to provide evidence that, across all African countries, households will borrow and sell assets in order to face these costs (Leive & Xu 2008). In the majority of countries, out-of-pocket expenditure was financed through borrowing and selling of assets for approximately 30% of all households; 50% of households who faced hospitalization coped with payments in the same way (Leive & Xu 2008). This coping strategy was found to be employed more so among those in the lower income strata than their wealthier counterparts and was particularly pronounced among rural communities (Leive & Xu 2008). According to the authors, households are only able to do so if: (a) the household is in possession of assets which can be sold; (b) the household

has the capacity to repay borrowed assets; (c) there exists sufficient social capital (Leive & Xu 2008). Another key finding reflected that households were at least 10% more likely to borrow and sell their assets if the level of inpatient spending was greater; this was consistent for eleven of the fifteen countries where the “effect was greatest in the Congo, Ethiopia and Ghana [as] households in the highest category of inpatient spending were 38%, 39% and 40%, more likely to cope by selling assets and borrowing” (Leive & Xu 2008, p. 851).

In 2008, Sagbakken et al (2008) explored the barriers and enabling factors to TB treatment in Ethiopia, concluding that the economic burden of treatment is a key determinant of treatment adherence through a dynamic process of interaction between individuals, their households, family members, social networks and employers (Sagbakken et al. 2008). Through a series of in-depth interviews and focus group discussions, the authors note that employment-related factors significantly restrict an individual’s ability to remain in treatment, particularly among those referred to as ‘daily labourers’ (defined as an individual who is not employed but convenes with other individuals to compete to be hired for the day) (Sagbakken et al. 2008). Many individuals in the private sector lost employment upon diagnosis due to the time-consuming nature of the treatment available to them as well an inability to continue working because of severe symptoms of illness, and daily labourers were no longer able to compete with their healthier counterparts (Sagbakken et al. 2008). These effects also resonated among family-members who accompanied individuals to treatment facilities (Sagbakken et al. 2008). Transport represented a significant barrier to access; many individuals discontinued treatment as they were unable to afford transportation (and/or provisions during travel) and were not strong enough to walk to treatment facilities which were usually a considerable distance away (Sagbakken et al. 2008). Sagbakken et al (2008) found that the majority of respondents prioritize their employment and income, interrupting or ceasing their treatment regimens, to ensure that they are able provide food to their respective households (Sagbakken et al. 2008). Their vulnerability is reflected by an Ethiopian health worker: “they rather live for a while, with money and their jobs, to eat and then die” (Sagbakken et al. 2008, p. 5).

The role of social networks and community is often a primary determinant of a household’s ability to cope with out of pocket payments, “patients with limited access to financial or practical help from relatives or friends experience that the total costs of attending treatment exceed[s] their available resources” (Sagbakken et al. 2008, p. 4). Despite TB’s association with a high degree of stigma and fear, Sagbakken et al (2008) found that during times of crisis, many individuals relied on reciprocal

arrangements between Ethiopian households, where encouragement and shared resources, which compensated for lost income, was an important determinant of accessing and adhering to treatment (Sagbakken et al. 2008). Nonetheless, the authors note that with time, levels of financial and practical support from community members diminished due to "financial and social exhaustion" (Sagbakken et al. 2008, p. 8) which was a huge concern considering the longevity of illness associated with TB, often leading to treatment termination and social exclusion (Sagbakken et al. 2008).

Consequences of the Medical Poverty Trap

As indicated in the preceding discussions, there is a substantial body of evidence illustrating the debilitating economic costs of illness. Though these costs may vary in type and intensity by socio-economic status, even those who are among the middle-income quintiles of their respective populations can be pushed into poverty when confronted with medical expenses, particularly when combined with loss of income and labour productivity (McIntyre, Thiede, et al. 2006). The incorporation of user-fees for public services over the past two decades coupled with an increasing trend for households to seek private services in response to quality weaknesses in the public sector has created considerable problems for the already frail health-systems in low and middle-income countries, particularly with regards to equity and coverage implications (Whitehead et al. 2001; Russell 2004). These problems have "deter[red] use of public health services, [particularly by those that are stricken by poverty,] so services are often ineffective in reaching the poor and generate less benefit for the poor than the rich... impos[ing] regressive cost burdens, with [low-income] households spending a higher proportion of their income on health care than better-off households" (Russell 2004, p. 147). The enormity and extent of this situation has been defined as 'the medical poverty trap' (Whitehead et al. 2001).

Untreated illness is perhaps the most dangerous and grave consequence of the medical poverty trap whereby individuals are unable to treat their illness purely because they do not have the financial ability to do so. This phenomenon has been empirically examined, and imposes devastating costs to both society and individuals, particularly because of its prevalence among the poor (Whitehead et al. 2001). In both the Caribbean and in rural India, of those who reported poor health, up to 20% and 17%, respectively, did not seek health care due to an inability to meet hospital, treatment and transport costs (Theodore 1999; Iyer & Sen 2000; Whitehead et al. 2001). Further, in China, a nation with stable economic growth that has been celebrated for its rural health network, 35-40% of rural respondents to Chinese household surveys reported untreated illness due to an inability to meet the financial demands

of doing so; 60% of those who were evaluated by a medical doctor and prescribed hospitalization did not do so for fear of the associated financial burden (Fu 1999; Whitehead et al. 2001).

The very nature of 'health shocks'—that the increases in health expenditure are unexpected and where the total expenditure needed to treat the illness is not known until after these costs have been incurred, forces households into the medical poverty trap, of which long-term impoverishment is another serious consequence (Whitehead et al. 2001; WHO Department of Health Systems Financing 2009; Leive & Xu 2008). The sale of assets, such as livestock or land imposes a "vicious cycle of increased economic vulnerability" (McIntyre, Thiede, et al. 2006, p. 862) as households relent on vital resources to their household's livelihood (McIntyre, Thiede, et al. 2006). Coping mechanisms, as outlined in previous sections, often come at a dire cost; households face lifelong debt repayment, exacerbated by exorbitant interest rates (underwritten by private lenders who seek to capitalize on the vulnerability of these groups) and a reduction of the consumption of essential, basic goods such as food and education to meet health care costs (Whitehead et al. 2001).

A key point is that ability-to-pay and payment are not one in the same; in a number of settings health care costs are highly regressive (Segall et al. 2000; Whitehead et al. 2001). As explained by McIntyre (2007, p. 5), "individuals should contribute to health care funding according to their ability to pay and should benefit from health services according to their need for care" (McIntyre 2007). The goal for countries now must be to develop health systems which circumvent regressive mechanisms by creating systems which protect households by including "cross-subsidies from the rich to the poor and from the healthy to the ill" (McIntyre 2007, p. 32).

AVAILABILITY OF HEALTH SERVICES & IMPLICATIONS FOR EQUITABLE ACCESS

The final dimension of access explores the role of physical access to health services, or availability. This dimension is concerned with whether or not the appropriate package of health services exist in the geographic areas that they are needed, when they are needed, in a way that ensures they are an appropriate distance from the communities they serve (based on the travel resources available to the community) (McIntyre et al. 2009; Thiede et al. 2007). When considering availability, it is useful to observe the degree of fit between health system factors such as: the physical location of facilities, the organization and qualification of personnel, the nature of services (quality, range, quantity, equipment

and whether they are mobile or 'in-house') and; household factors such as: the health needs of the community, the demographics of the population, transport options as well as the appropriateness of opening hours (McIntyre et al. 2009; Thiede et al. 2007).

In 2009, Goudge et al (2009) combined results of a household survey with qualitative methods to understand availability barriers to health care for the chronically ill in Mpumalanga, South Africa (Goudge et al. 2009). This area is recognized as predominantly rural, with poor sanitation and road infrastructure, little access to electricity and high unemployment rates; the findings of this study are therefore useful in gaining insight into the barriers of access for low-income communities. The authors identify availability as a central factor affecting access across three key areas: (a) insufficient and ineffective clinical services; (b) interrupted drug supplies and; (c) inadequate transport options (Goudge et al. 2009). Respondents described a number of nursing professionals at their community health clinics who displayed insufficient knowledge to treat certain conditions as well as a lack of equipment including key diagnostic tools such as blood pressure cuffs, and blood glucose measurement devices (Goudge et al. 2009). Patients were forced to repeatedly, personally finance travel to distant district hospitals where these devices were available at higher consultation fees; "for highly vulnerable households, repeat visits generated cost burdens amounting to 30-50% of monthly income" (Goudge et al. 2009, p. 11). Attending the hospital was only an option for those who could afford the taxi fare, as ambulatory services at community health clinics were "not available to take [individuals] to hospital or return [them] back to the clinic after [their] inpatient stay" (Goudge et al. 2009, p. 12). Though ambulances were physically present, drivers were reportedly unavailable or the vehicles were not deemed roadworthy (Goudge et al. 2009). In several instances, patients reported having to cease TB treatment and became critically ill (Goudge et al. 2009). Furthermore, staff shortages, the lack of continuity of care by the same physician, due to high turnover in rural community clinics and a "lack of a system for reimbursing nurses for tracing patients" (Goudge et al. 2009, p. 12) lead to approximately 66% of identified TB cases resulting in mortality and only "four of the eleven [identified] chronic cases in vulnerable households, and 5 out of 8 [identified] chronic illnesses in secure households being treated regularly" (Goudge et al. 2009, p. 10).

The majority of respondents also explained their frustration over a lack of medication at public clinics who most often reacted by self-treating their illnesses, visiting retail pharmacies and obtaining medications without prescriptions (Goudge et al. 2009). This practice has become commonplace in

many low and middle income countries whereby drugs are sold without prescriptions by unqualified individuals at retail pharmacies who will often overprescribe medication, motivated by financial incentives, which leads to irrational drug use and drug resistance (Whitehead et al. 2001). Furthermore, these practices, born out of frustration and a lack of options for ill individuals and their households, often significantly contribute to the inequity of the medical poverty trap (Whitehead et al. 2001). Expenditure for medicines outside of health facilities are exorbitant, particularly when individuals are resistant to first or second line disease treatment options and are forced to obtain the pricier third line options (Whitehead et al. 2001). These retail outlets usually operate during weekends when public health facilities are closed and are generally a closer proximity to rural households than community clinics and hospitals, both factors of which were deemed to contribute to treatment seeking in the retail sector by Smith et al (2011) in a study of access to malaria treatment in rural Kenya (Smith et al. 2011).

In a similar vein, Chuma et al (2010) illustrated the effect of physical distance from health facilities on treatment seeking behaviour in rural Kenya (Chuma et al. 2010). According to their findings, approximately 33% of respondents who engaged in self-treatment for malaria through a visit to a retail pharmacy reported that they would have opted to visit a public health facility if it had been closer (Mbagaya et al. 2005; Chuma et al. 2010). Similarly, in another district, 74% of respondents reported that they visited a public health facility to receive malaria treatment simply because it was close to where they resided (Munguti 1998; Chuma et al. 2010).

Chuma et al (2010) also communicate drug-related supply-side barriers to access which further substantiate the findings of Goudge et al (2009) and Smith et al (2011) (Chuma et al. 2010; Goudge et al. 2009; Smith et al. 2011). Public facilities in rural Kenya were regularly confronted with drug shortages due to failures in central-level drug deliveries and poor drug need-assessments which failed to respond to the seasonal fluctuations of malaria incidence (Chuma et al. 2009; Chuma et al. 2010). As in the aforementioned cases, individuals defaulted to self-treatment, purchasing drugs from retail vendors without prescriptions where quality was not controlled and dosage information not provided (Chuma et al. 2010). Chuma et al (2010) however, note how poor quality of care within public facilities also served a critical role in access to malaria treatment where health workers demonstrated poor and inappropriate prescribing practices, even when medications were in stock at facilities (Chuma et al. 2010).

Rural health facilities have become accustomed to sporadic drug supplies which has created fear among health workers of 'stock-outs' (Chuma et al. 2010). As a result, health workers have been seen to disregard national malaria prescription guidelines whereby health workers make personal judgments over who they believe is deserving enough to receive treatment (Wasunna et al. 2008; Chuma et al. 2010). Furthermore, many health workers simply do not receive adequate training of malaria drug prescribing practices, considered to be the result of staff shortages at rural facilities and a resultant lack of supervision (Wasunna et al. 2008; Chuma et al. 2010). According to a study of prescribing practices of anti-malarial medications in Kenya, of all children who had displayed malarial symptoms (as defined by national guidelines), only 26% were prescribed amodiaquine (the nationally recommended anti-malarial drug) and 23% of children were recorded to have left health facilities with no treatment or prescription for treatment which illustrates the potentially lethal effects of poor quality of care (Wasunna et al. 2008; Chuma et al. 2010).

As highlighted in the preceding discussions, the world's poor and marginalized groups are undeniably suffering higher rates of illness, disease and mortality. While not exclusively, one of the largest, most significant and most avoidable contributors to these health distributions are the inequitable barriers which exist in accessing health services. It is clear that certain populations are being culturally, physically and financially prohibited from accessing the services they need to treat their illnesses and reverse current trends. A pro-poor, equity-based approach requires that health-care services pay special attention to the needs of the most disadvantaged groups.

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PART C: JOURNAL MANUSCRIPT

An Analysis of Adherence & Equity in Access to TB DOTS Services in Mitchell's Plain

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Objectives: The control of tuberculosis (TB) in South Africa has fallen short of the targets outlined by the World Health Organization and without improvement, TB is expected to have grave consequences for both the mortality and morbidity of South Africans as well as crippling financial consequences for the public health system. While services in the public sector are free at the point of use, little is known about overall access barriers and their implications for treatment adherence. This paper explores these barriers from the perspective of TB patients enrolled in Directly Observed Treatment, Short-Course (DOTS) in Mitchell's Plain, South Africa.

Methods: Using a comprehensive framework of access, interviews were conducted with 334 TB patients to assess barriers across the dimensions of availability, affordability and acceptability. Summary statistics were computed and comparisons of access barriers between adherent and non-adherent groups, and between socioeconomic groups were explored using bivariate, multivariate linear and logistic regressions.

Results: Among the respondents, 244 (73.05%) met the criteria for adherence (i.e. reported that they had never missed a dose of TB medication) while 90 (26.95%) met the criteria for non-adherence. Marital status, age, birth province, costs of self-care and costs of other providers were found to be significantly associated with adherence (P-values <0.05). There was no significant evidence of inequalities in access by socioeconomic status (all P-values > 0.05).

Conclusions: Our findings indicate that non-adherence is not associated with access barriers and there is therefore no evidence of inequity in adherence to DOTS TB- treatment. In addition, our findings show that there is no significant evidence of inequalities in access to DOTS TB-services in Mitchell's Plain, by socioeconomic status. This study discovered that there is a need to explore the high costs of using TB-services, specifically high transport costs which are associated with the frequency of clinic visits.

Keywords: Health service accessibility, Tuberculosis (TB), Directly observed therapy, Patient Adherence, Availability of health services, Patient acceptability of health services, Equitable access

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ABSTRACT

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Introduction

Tuberculosis (TB) represents one of the most pressing global health issues and since 1993, has been considered a public health emergency [1]. According to the World Health Organization (WHO) (2011), TB is a worldwide pandemic whereby low and middle income countries (LMICs) carry 90% of the worldwide burden; Africa assumes 26% of cases of TB, while 59% of all new cases are emerging from Asian countries (WHO 2010b; WHO 2011a; Lawn & Zumla 2011). The past two decades have seen an escalation in TB morbidity; prevalence estimates in 1993 of 7-8 million cases have grown to 8.5-9.2 million cases in 2010 – more than at any other time in history [1]. TB is accountable for the most deaths from an infectious disease worldwide, after HIV/AIDS, with estimates reaching 1.2–1.5 million deaths in 2010 [1]. Incidence rates of TB have declined marginally at a rate of almost 1% per year since 2002; however, the absolute burden continues to increase worldwide [1], [3].

South Africa currently has the third-highest TB burden in the world with TB notification rates increasing fivefold over the last twenty years [4]. In 2008, TB incidence was an estimated 940

cases per 100 000 people [5]. A serious contributor to the burden of TB in South Africa has been the emergence of multi-drug resistant (MDR) strains of the mycobacterium tuberculosis bacilli, the organism which causes TB [6]. Those that become infected with MDR are subject to extended, complex and extremely expensive treatment regimens which have poor success rates and often fatal outcomes [6]. It has been estimated that treatment for MDR costs 100 times the cost of treating drug-susceptible TB [6]. Furthermore, the impact of the HIV/AIDS epidemic has been considerable; the weakened immune systems of HIV/AIDS infected individuals puts them at a greater risk of acquiring TB. In 2007, approximately 40% of all notified TB cases in South Africa were tested for HIV/AIDS and 73% were estimated to be positive [4]. Over the next five years the epidemiological profile of TB in South Africa is likely to show increasing rates of infection, more pronounced in the provinces of KwaZulu-Natal, Mpumalanga and Gauteng, which have the fastest-growing HIV infection rates in the country [6].

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Availability	Affordability	Acceptability
Mode & Cost of Transport	Total Expenditure (Direct & Indirect) on Health Care including: Expenditure to reach facility Expenditure on self-care Expenditure on other providers Lost wages as a result of facility visit	Perceptions of Staff Attitudes, Facility Cleanliness, Length of Queues, and Community Judgment (as a proxy for Stigma), Confidentiality and Privacy.
Travel Time to Facility	Healthcare Costs as a Proportion of Household Expenditure	Provider expectations of Patient
Waiting Time at Facility	Ability to Borrow Money to Pay for Healthcare Expenses	Perceptions of The Effectiveness of Treatment
Availability of Government 'Disability' Grants	Receipt of Government 'Disability' Grants	

Table 1. Dimensions of Access

Adapted from: [7], [8]

In 1995, the South African government revised the National Tuberculosis Control Program (NTCP) based on the WHO's Directly Observed Treatment, Short -Course (DOTS) guidelines which necessitate: (1) a sustained government commitment to prioritize TB control; (2) the diagnosis of TB through sputum microscopy; (3) standardized and supervised treatment in a supportive environment; (4) uninterrupted drug supply and; (5) regular monitoring of patients and health systems [9]. Treatment of active tuberculosis is done with a standardized range of anti-TB drugs, which must be monitored and administered daily by public health facilities or community health workers, over a period of approximately six months, in order to ensure that individuals take and complete their course of medication [10].

Adoption of the DOTS strategy in South Africa in 1996, and significant investments in TB control have helped the country achieve 100% population coverage (defined as the proportion of population living in administrative areas with access to DOTS services) of DOTS TB-treatment, free at the point of use, and allowed for the adoption of new and improved TB drugs (with shorter periods of treatment); superior TB diagnostic tools; improved TB registration mechanisms; and clear performance targets. While these are considerable achievements, the case detection rate remains less than 60% with treatment success rates in 2008 at 76%, falling short of the WHO targets of 70% and 85%, respectively [5]. Estimates by the South African Medical Research Council have indicated that if control efforts do not improve, an anticipated 3.5 million new cases of TB will develop with approximately 90,000 deaths over the next decade [6].

Since the democratization of South Africa in 1994, the government has established its commitment to equity in health service delivery and financing by directing health policies and programs to vulnerable groups and diseases of poverty [11], [12]. Broadly, health policy has been centered on improving access to health care services, yet, despite a considerable body of research dedicated to conceptualizing access, there has long-existed a cloud of ambiguity surrounding a universally-acceptable, empirical definition of the term, particularly when being operationalized to evaluate health systems in LMICs [7], [13–15]. As explained by Thiede et al (2007), "...if the access concept is not well understood, comprehensive evidence on what should be done to promote equitable health systems cannot be gathered"[7].

In earlier literature, 'access' was primarily viewed in terms of two factors – money fees at the point of use and distance travelled to use health care services [16]. Others have defined access as use of services; both in terms of actual use (absolute terms) and in terms of the differential use of health services across groups and individuals with diverse needs (relative terms) [8], [17–20]. The most recent contributions to the study of access, particularly in its application to LMICs has explored access as a unique experience; the empowerment of individuals

to use and benefit from health services [8]. By this definition, access to health services can only be understood when characteristics of the individuals and characteristics of the health system are considered together and relative to one another as they are constantly engaging in a "dynamic process of interaction" [8]. The degree of access to a particular health service is therefore governed by the relative fit between the system and the individuals it serves across *all* individual and system factors which have the potential to affect the freedom to use health care. Under this conceptual framework, these individual and system factors can be grouped into three dimensions: availability (physical access factors), affordability (financial access factors) and acceptability (cultural access factors), as a starting point for empirically investigating access and for developing health policy strategies that can address these barriers [7], [8].

Since the World Health Organization's Alma-Ata Declaration (1978) which promoted the need to improve the health profiles of those most in need, the WHO has defined equity in health as a situation in which "everyone should have a fair opportunity to attain their full health potential [whereby] no one should be disadvantaged from achieving this potential, if it can be avoided" [21], [22]. Equity has endured as a central goal for global public health policy and practice. A health inequity exists if health inequalities are considered to be: (1) unfair; (2) unjust; (3) avoidable and; (4) unnecessary; and further, that tagging a difference in the health profile of one group as inequitable involves a moral and ethical judgment of the fairness of the causes of the inequalities [22–24]. What is made consistently clear from all discussions on equity, particularly within the context of health and health services is the fact that it can only be achieved if there exists a fair opportunity for all to achieve health. This understanding reflects the central role of access; if health services are the means by which populations and individuals are granted the opportunity to achieve their full health potential then it undoubtedly follows that equity in health is dependent on the equity which exists in access to health services [22], [24].

The effects of the TB are particularly pronounced among the 13.3 million South Africans living in poverty [25]. It is widely documented that these groups face higher rates of mortality and morbidity relative to their better off counterparts, yet despite their increased needs, use less health services [26]. In the context of TB, the success of treatment and ultimately the control of the disease are hinged on assured daily access to health care for a prolonged treatment period. According to the WHO (2003), poor adherence to anti-tuberculosis medication is among the most significant barriers to its global control [27]. This is particularly due to the fact that TB is a communicable disease and as a result, poor adherence to treatment has implications at both the individual and community levels through transmission,

morbidity, mortality and drug resistance [27]. Where non-adherence is the result of unfair, unjust, avoidable or unnecessary forces which prevent access to TB medications, equity concerns intensify its importance.

What is consistent from the majority of literature which examines adherence to TB treatment is the fact that adherence cannot be predicted or controlled by a single factor. Likewise, "non-adherence is a complex, dynamic phenomenon with a wide range of interacting factors impacting treatment-taking behavior" [28]. Adherence barriers take effect against an array of facilitating factors, and the final decision about treatment adherence depends on which factors predominate [29]. There are a number of documented ways in which the acceptability, affordability and availability of TB treatment affects patient adherence. Even where TB treatment is provided free at the point of use, adherence can be compromised by the direct costs of: transportation; extraordinary dietary requirements as a result of the illness and/or treatment related side-effects and; the indirect costs of productive time losses incurred while travelling and receiving daily treatment. The location of treatment facilities and the need for transportation has also been linked to reduced adherence reflecting the impact of availability-related forces. Furthermore, cultural factors such as the stigma attached to TB, the knowledge about TB and belief in the efficacy of the medication as well as the nature of relationships between the health provider, social networks and the patient also have proven to be critical forces in influencing treatment adherence [27].

Despite the importance of equitably accessible TB treatment, very little research exists which explores access to DOTS services and the barriers of TB-treatment adherence in South Africa making it particularly difficult for the government to tailor the provision of treatment and health promotive interventions in a way that ensures patients are able to initiate and complete their treatment. Furthermore, few studies have explored whether the factors which influence access vary according to the socioeconomic status of the patient. This study aims to explore the relationship between access to DOTS services (i.e. the availability, affordability and acceptability of TB-treatment) and patient adherence, and to examine whether service access is equitable. Findings from the study may provide evidence to assist in evaluating the success of current TB policy and may further assist in developing strategies and interventions which mitigate the barriers to both accessing and adhering to DOTS TB-treatment, in order to achieve the TB-related targets outlined by the WHO.

Methods

Study Design & Conceptual Framework of Access

This study is based on data derived from Phase 1 of the Researching Equity in Access to Health Care (REACH) project, a five-year study of health system access in South Africa which commenced in 2007. Details regarding the survey methodology are available in published sources [30]. Briefly, an exit-interview style, interviewer administered questionnaire was used to gather socioeconomic and demographic data, data regarding the individual's dwelling characteristics, household income, an estimate of monthly household expenditure and household asset ownership, as well as data regarding key barriers to DOTS TB-treatment accessibility, from the perspective of the patients. The data set was collected between 2008 and 2009 by the REACH research team, an experienced multi-disciplinary team of health economics, systems, policy and social science researchers.

This study draws on a comprehensive conceptual framework of access whereby access is assessed in terms of the *degree of fit*

between the needs of the population and the availability, affordability and acceptability of the health system response [7], [8]. Each of these access dimensions can be represented by a number of clear and measurable variables, examples of which have been outlined in Table 1. A fundamental part of the framework is the understanding that while each dimension is concerned with its own set of issues: affordability being primarily concerned with factors related to financial access; availability being concerned primarily with those factors which are related to physical access; and acceptability being concerned with those factors related to cultural access; that the dimensions are interrelated and affect the interaction between the health system and its users [7], [8]. In this way, access to health services can only be achieved and understood if all dimensions are addressed and considered from both the health care system (supply-side) and individual (demand-side) perspectives [7], [8].

Within this study, the availability variables included the travel time for the patient to reach the TB-treatment facility, the time taken within the facility, whether patients were required to travel on foot and how often they were required to visit the facility to fetch their TB medications. Affordability variables incorporated coping mechanisms by asking whether or not the patient was required to borrow money in order to meet the costs of treatment and also included information on monthly health care expenditure including: the direct costs of seeking treatment, expenditure on other providers (e.g. traditional healers) and expenditure on self-care (e.g. special dietary requirements). These measures were combined and contrasted with the patient's reported overall monthly household expenditure to determine whether costs were catastrophic (in this instance defined by whether the total costs of care exceeded 10% of monthly household expenditure).

With regards to acceptability, respondents were asked to report their perceptions of staff attitudes (by reporting whether they felt respected by staff and whether they felt that staff members were too busy to answer questions), facility cleanliness, queues and community stigma.

Setting & Participants

This study focuses on individuals using TB treatment services (n=334) in Mitchell's Plain. Mitchell's Plain was purposively sampled by the REACH research team to represent a metropolitan, urban setting of South Africa. The Mitchell's Plain sub-district belongs to the Cape Town Metropolitan health district, located in the Western Cape Province in the south-west region of South Africa. Based on Censuses projections from 2001, Mitchell's Plain holds a population of an estimated 460,686 people – 14% of the total population of the Cape Town Metropolitan health district [31]. The population of Mitchell's Plain is largely poor whereby 30% of households fell below the poverty line in 2003 and 41% lived in informal dwellings [31]. Tuberculosis rates in the Western Cape are among the highest in the country; between 1997 and 2003, the Cape Town TB Control Report showed an increase of 66% in reported cases over the seven years, reflecting a growing population, migration, improved case detection and increased burden of disease, mainly in regions where HIV/AIDS is most prevalent [31], [32]. Currently, the Western Cape's incidence rate of TB is 909 cases per 100 000 [33].

In Mitchell's Plain, a probability proportional to size method was used to choose five facilities (Crossroads I, Lentegur, Mzamomhle, Phumlani and Weltevreden) out of those providing TB services, with a fixed cluster size, using data on the total number of users in each facility at the time of research. With this method, some facilities can be sampled twice so the sample size within facilities varied slightly across the five facilities. Such a

sampling approach allows for results to be generalizable to TB users within the sub-district. Within facilities, systematic random sampling methods were used to choose respondents. A total of 334 patients, made up of 47% males and 53% female, were interviewed across all five facilities in Mitchell's Plain. Subjects were included if they had been receiving TB treatment for at least two months, were over the age of eighteen and were deemed to be sufficiently well to participate, by facility staff. After obtaining written informed consent, interviews were administered by trained fieldworkers using a structured exit interview questionnaire in the language of each subject's choice.

Approval for the original study, of which this analysis is a subcomponent, was granted by Ethics committees at the University of Cape Town, University of Witwatersrand and the University of KwaZulu-Natal and further permission to conduct research was granted by both provincial and local health authorities in South Africa.

Data Analysis

Completed questionnaires were inspected by a data collection coordinator for accuracy. Once approved, responses were double entered into a data entry platform and exported to STATA/SE 11.0 for analysis.

Parameter	n (%)	Never Missed TB Medication (Adherent) N=244 (73.05%)		Missed TB Medication (Non-Adherent) N=90 (26.95%)		Statistical Significance (P-value)
		n	% [†]	n	% [†]	
Sex						
Female	178 (53.29)	129	52.87	49	54.44	0.798
Male	156 (46.71)	115	47.13	41	45.56	
Education						
No schooling	13 (3.89)	12	4.92	1	1.11	0.209
Some Schooling	265 (79.34)	189	77.46	76	84.44	
Completed High school	56 (16.77)	43	17.62	13	14.44	
Disability Grant						
Yes	71 (21.26)	52	21.31	19	21.11	0.968
No	263 (78.74)	192	78.69	71	78.89	
Province Where Born						
Western Cape	93 (28.18)	56	23.14	37	42.05	0.002
Eastern Cape	226 (68.48)	176	72.73	50	56.82	
Other	11 (3.33)	10	4.13	1	1.14	
Employment Status						
Unemployed	264 (79.04)	193	79.10	71	78.89	0.967
Employed(Full-time/Part-time)	70 (20.96)	51	20.90	19	21.11	
Race						
African/Black	277 (83.43)	206	85.12	71	78.89	0.332
Coloured	54 (16.27)	35	14.46	19	21.11	
White	1 (0.30)	1	0.70	0	0	
Marital Status						
Married	77 (23.05)	65	26.64	12	13.33	0.004
Living with Partner	11 (3.29)	9	3.69	2	2.22	
Widowed	9 (2.69)	8	3.28	1	1.11	
Divorced/Separated	30 (8.98)	26	10.66	4	4.44	
Single	207 (61.98)	136	55.74	71	78.89	
Age						
18-25	57 (17.07)	33	13.52	24	26.67	0.017
25-40	177 (52.99)	131	53.69	46	51.11	
40-60	88 (26.35)	70	28.69	18	20.00	
Over 60	12 (3.59)	10	4.10	2	2.22	
		Median (IQR)		Median (IQR)		
		34 (42-27)		30 (38-23.5)		
Socioeconomic Status						
Poor	167 (50.00)	124	50.82	43	47.78	0.622
Rich	167 (50.00)	120	49.18	47	52.22	

[†] Rounding may result in this column not summing to 100%

Table 2. Demographic & socioeconomic features of those who report missed TB medication and those who do not

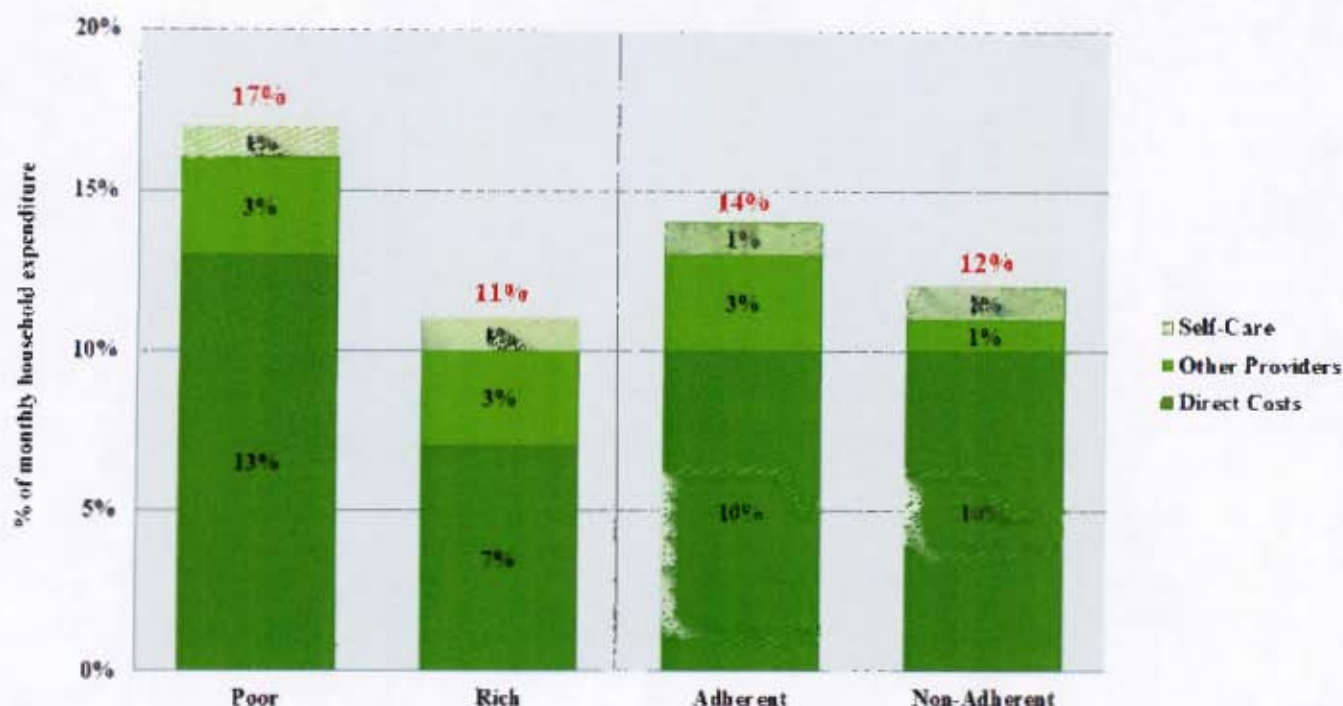


Figure 1 Average expenditure on self-care, direct costs and other providers as a percentage of monthly household expenditure, by socioeconomic and adherence group.

The exact effect of the premature termination of treatment or of poor compliance with a prescribed TB-regimen, on treatment outcome is as yet undefined and known to be a dynamic process influenced by a range of factors. It is widely accepted that poor adherence to anti-tuberculosis medication is among the most significant barriers to its global control and that a key component of adherence involves taking prescribed medication and following medical direction (i.e.: medication adherence) [27]. In light of this understanding, discussions and specific conclusions regarding 'adherence' or 'non-adherence' refer to adherence measured using a process-oriented approach whereby adherence is narrowly defined as having never missed a dose of TB medication and correspondingly, non-adherence is defined as having missed a dose of TB-medication. This study does not comment on the clinical impact or outcomes of non-adherent patients.

Summary statistics and cross-tabulations were used to describe the socioeconomic and demographic characteristics of adherent and non-adherent patients. The factors constraining access (the variables which measure affordability, acceptability and availability) were then assessed relative to adherence and SES using the same method. Bivariate associations between categorical variables were compared using the Mantel-Haenszel chi-square or Fisher's exact test. Associations between continuous variables were tested using the Student's *t* test (for means) and Wilcoxon rank-sum tests (for medians). A *P* value less than 0.05 was accepted as statistically significant.

Multivariate logistic and linear regressions were used to test for differences in access, by SES, after controlling for level of education, age, sex, marital status and the province where the respondent was born. This allowed for us to focus specifically on SES related access barriers and to test for inequalities in these barriers while holding other measures of social disadvantage constant.

Measuring Socioeconomic Status

The socioeconomic measure was constructed using Multiple Correspondence Analysis (MCA) of the characteristics of the respondents and their households and an asset index approach was used to allocate respondents into socioeconomic classes. Many have argued that the socioeconomic status (SES) is most effectively measured by household income, consumption or expenditure however this data is rarely available within LMICs and is challenging to collect [30]. Most often, Principal Component Analysis (PCA) is used to generate SES indices however, the majority of data collected in this study was not continuous or normally distributed and as such, this technique would not be optimal [31].

As an alternative, MCA allows SES measures to be generated for nominal categorical data. Based on the results of the MCA, the assets included in the SES measure were: the type of toilet facility used, the household's source of energy for cooking, and ownership of a landline telephone, radio, television, DVD player, vehicle, car, bicycle, livestock or a fridge. After prediction, SES was categorized into two groups of patients: poor and rich.

Results

Socioeconomic & Demographic Factors

Table 2 documents key socioeconomic and demographic variables of the study participants. Of the 344 respondents, 53.29% were female and the majority of the respondents (52.99%) were aged between 25 and 40 years. As shown in Table 2, 83.43% of those that were interviewed were African, 61.98% were single and 68.48% were born in the Eastern Cape province of South Africa.

Among the respondents, 244 (73.05%) met the criteria for adherence (i.e. reported that they had never missed a dose of TB medication) while 90 (26.95%) met the criteria for non-adherence (i.e. reported that they had missed a dose of TB medication). The median (interquartile range) age of the participants was 34 years (42-27) and 30 years (38-23.5) for the adherent and non-adherent groups.

Age was found to be significantly associated with adherence ($P=0.017$). Older age groups tended to have a higher proportion of adherent patients when compared to non-adherent patients. Consequently, the youngest age group had a higher proportion of non-adherent patients.

A larger proportion of non-adherent participants were single: 78.89% of non-adherent respondents and 55.74% of adherent respondents were single. Correspondingly, there was a two-fold increase in being married in the adherent group where 26.64% of respondents were married compared to 13.33% in the non-adherent group. Marital status was seen to be significantly related to adherence ($P=0.004$).

The majority of adherent and non-adherent respondents were born in the Eastern Cape province (72.73% and 56.82%, respectively) although there was a nearly two-fold increase in the proportion of participants who were born in the Western Cape province in the non-adherent group where 42.05% of non-adherent participants were born in the Western Cape versus 23.14% of adherent participants. Differences in adherence by province of birth were found to be statistically significant ($P=0.002$).

The asset index indicated that 47.78% of non-adherent patients belonged to the poorest socioeconomic group. This proportion was slightly higher among adherent patients where 50.82% of patients were among the poorest respondents. Nonetheless, the relationship between socioeconomic status and adherence was not found to be statistically significant. Other socioeconomic and demographic parameters including level of education, receipt of a disability grant, employment status and race were also not found to be associated with adherence.

Access & Adherence

Table 3 documents the results of the bivariate, unadjusted analysis of the association between each of the access variables and adherence.

In terms of the availability of TB-services, the majority (67.66%) of respondents reported that they travelled on foot in order to reach the facility; this proportion translated to 66.80% of adherent patients and 70% of non-adherent patients. 92.79% of respondents received a form of facility based daily-DOTS TB-treatment which required them to visit the facility on a daily basis to receive medication. A slightly higher percentage of non-adherent patients were on facility daily-DOTS compared to adherent patients (95.56% versus 91.77%, respectively). The median (interquartile range) travel time to reach the facility and return home was slightly shorter for non-adherent patients (17.50 (30-10) minutes versus 20 (30-10) minutes for adherent patients. Nonetheless, no significant association was found between any of the availability variables and adherence.

In terms of affordability, the monthly expenditure on self-care and the monthly expenditure on other providers were both found to be significantly associated with adherence. Self-care expenditure refers to the monthly costs incurred by the patient for over-the-counter medications, special foods as a result or requirement of treatment and/or expenditure on traditional medications. The mean (\pm standard deviation) monthly expenditure on self-care for adherent patients was R7.51 (\pm R29.50) versus R5.00 (\pm R22.16) for non-adherent patients (P -value: 0.026). Expenditure on other healthcare providers includes costs incurred from visiting general practitioners (GPs) or traditional healers. The mean (\pm standard deviation) expenditure on other healthcare providers for adherent patients (R32.54 \pm R106.63) was nearly three times that of non-adherent patients (R11.25 \pm R23.13) (P -value: 0.048).

The total expenditure on TB-treatment was catastrophic (i.e. greater than 10% of the respondent's household expenditure) for 33.47% of adherent patients and 28.89% of non-adherent patients although this association was not found to be statistically significant. Figure 1 depicts the breakdown of healthcare costs as a percentage of total household expenditure. According to the graph, the direct costs of treatment and the expenditure on self-care represent similar proportions of overall health expenditure (10% and 1%, respectively) for both adherent and non-adherent groups. Expenditure on other providers represents 3.00% of the total household expenditure for adherent patients and 1.00% for non-adherent patients. Total healthcare costs for adherent patients, on average, accounts for 14.00% of total household expenditure and 12.00% of total household expenditure for non-adherent patients.

With regards to perceptions of the acceptability of TB services, none of the variables were found to be significantly associated with adherence. Distinctly, 43.54% of respondents reported that queues were too long. In addition, perceptions of respectful treatment from facility staff were seemingly more problematic for adherent patients whereby 21.31% agreed that the staff did not treat patients with respect (compared to 15.56% of non-adherent patients).

Access & Equity

Table 4 documents the results of the bivariate, unadjusted analysis and the multivariate analysis of the association between SES and each of the access variables. The results of the multivariate regressions are shown as adjusted Odds Ratios or coefficients. Using the 'poor' respondent group as the referent, these results summarize differences between 'rich' and 'poor' respondents across each dependent access variable, after controlling for level of education, age, sex, province of birth and marital status.

Using an asset index computed by pooling household and individual data of respondents, we were able to compare the barriers faced by respondents of different socioeconomic groups in accessing TB-services. The resulting index achieved two, equally spaced groups, indicating no problems with clumping.

As shown in Table 4, there was no statistically significant evidence of inequalities in access by SES (all P -values > 0.05). We explored grouping the distributions into four socioeconomic quintiles, but as before, no significant differences were detected (data not shown).

In terms of availability, poor respondents were more likely to report having travelled on foot whereby 71.86% of poor respondents travelled on foot compared to 63.47% of rich respondents. The travel time to reach the facility was higher for poor respondents whereby the median (interquartile range) travel time for the poor was 20.00 (30.00-10.00) minutes compared to 15.00 (30.00-10.00) minutes for the rich.

In terms of affordability, the rich were seen, on average, to spend more on other providers, self-care and on the direct costs of seeking treatment (i.e. transport), when compared to the poor. Overall, total monthly expenditure on health care represented a more substantial burden for poorer respondents who, on average, spent 17.59% of their total household expenditure compared to the rich who spent 10.42% of their total household expenditure on seeking treatment. Costs were catastrophic for a larger proportion of the poor (34.15%) when compared to the rich (30.25%). Figure 1 depicts the breakdown of healthcare costs as a percentage of total household expenditure. According to the graph, the expenditure on other providers and on self-care

Parameter	Never Missed TB Medication (Adherent) N=244 (73.05%)			Missed TB Medication (Non-adherent) N=90 (26.95%)		Statistical Significance
	n (%)	n	% [‡]	n	% [‡]	(P-value)
AVAILABILITY						
Did patient travel by foot?						
Yes	226 (67.66)	163	66.80	63	70.00	0.579
No	108 (32.34)	81	33.20	27	30.00	
How often is patient required to visit the facility to collect medication?						
Daily	309 (92.79)	223	91.77	86	95.56	0.337
Weekly	14 (4.20)	10	4.12	4	4.44	
Monthly	8 (2.40)	8	3.29	0	0.00	
3 Times each Week	2 (0.60)	2	0.82	0	0.00	
Median (IQR)						
Time taken to travel to facility and home again (minutes)						
	20 (30-10)	20 (30-10)		17.50 (30-10)		0.584
Time taken to fetch medicines during last visit (minutes)						
	15 (30-10)	20 (30-10)		15 (30-10)		0.103
AFFORDABILITY						
Mean ± SD						
Monthly expenditure on attending health facility in South African Rands (transport, phone, food, etc.)						
	75.22 ± 180.13	80.86 ± 200.42		60.00 ± 107.26		0.774
Monthly expenditure on self-care in South African Rands (over the counter medications, special foods, traditional medications)						
	6.84 ± 27.70	7.51 ± 29.50		5.00 ± 22.16		0.026
Monthly expenditure on other healthcare providers in South African Rands (GPs, traditional healers etc.)						
	26.80 ± 94.32	32.54 ± 106.63		11.25 ± 43.69		0.048
Total monthly expenditure on healthcare as a percentage of household expenditure						
	14.02 ± 31.57	14.81 ± 34.25		11.96 ± 23.13		0.265
n (%)						
Was patient required to borrow money to pay for health care?						
Yes	45 (13.47)	32	13.11	13	14.44	0.752
No	289 (86.53)	212	86.89	27	85.56	
Total expenditure on health care > 10% household expenditure						
Yes	105 (32.21)	79	33.47	26	28.89	0.428
No	221 (67.79)	157	66.53	64	71.11	
ACCEPTABILITY						
Patient reported that the health worker was too busy to answer his/her questions						
Yes	37 (11.11)	28	11.52	9	10	0.695
No	296 (88.89)	215	88.48	81	90	
Patient reported that queues were too long (**Data for one patient was missing)						
Yes	145 (43.54)	106	43.44	39	43.82	0.951
No	188 (56.46)	138	56.56	50	56.18	
Patient reported that staff do not treat patients with respect						
Yes	66 (19.76)	52	21.31	14	15.56	0.241
No	268 (80.24)	192	78.69	76	84.44	
Patient reported that facility was dirty						
Yes	47 (14.11)	32	13.17	15	16.67	0.416
No	286 (85.89)	211	86.83	75	83.33	
Patient reported feeling judged by their community for attending the TB facility						
Yes	37 (11.08)	25	10.25	12	13.33	0.425
No	297 (88.92)	219	89.75	78	86.67	

[‡] Rounding may result in this column not summing to 100%

Table 3. Relationships between the Availability, Affordability & Acceptability of DOTS Services and Missing TB Medication

Parameter	Socioeconomic Status		Statistical Significance (P-value)	Multivariate or Adjusted Odds Ratio ^a	Statistical Significance (P-value)	Confidence Interval
	Rich n (%)	Poor n (%)				
AVAILABILITY						
Did patient travel by foot?						
Yes	106 (63.47)	120 (71.86)	0.101	0.770	0.362	0.439 – 1.351
No	61 (36.53)	47 (28.14)				
Median (IQR) Median (IQR)						
Time taken to travel to facility and home again (minutes)						
	15 (30-10)	20 (30-10)	0.569	1.120	0.525	-2.347 – 4.586
Time taken to fetch medicines during last visit (minutes)						
	15 (30-10)	15 (30-10)	0.910	1.302	0.721	-5.870 – 8.473
Mean ± SD Mean ± SD						
AFFORDABILITY						
Monthly expenditure on attending health facility in South African Rands (transport, phone, food, etc.)						
	75.86 ± 150.75	74.59 ± 205.69	0.487	-4.771	0.840	-51.398 – 41.855
Monthly expenditure on self-care in South African Rands (over the counter medications, special foods, traditional medications)						
	7.55 ± 28.93	6.12 ± 26.49	0.287	-0.935	0.774	-7.349 – 5.478
Monthly expenditure on other healthcare providers in South African Rands (GPs, traditional healers etc.)						
	30.58 ± 105.77	23.02 ± 81.43	0.141	11.31	0.457	-18.602 – 41.237
Total monthly expenditure on healthcare as a percentage of household expenditure						
	10.42 ± 18.91	17.59 ± 40.10	0.858	-6.66	0.119	-15.055 – 1.734
n (%) n (%)						
Was patient required to borrow money to pay for health care?						
Yes	24 (14.37)	21 (12.57)	0.631	1.620	0.213	0.758 – 3.461
No	143 (85.63)	146 (87.43)				
Total expenditure on health care > 10% household expenditure						
Yes	49 (30.25)	56 (34.15)	0.451	0.807	0.447	0.464 – 1.403
No	113 (69.75)	108 (65.85)				
ACCEPTABILITY						
Patient reported that the health worker was too busy to answer his/her questions						
Yes	23 (13.77)	14 (8.43)	0.121	1.413	0.387	0.646 – 3.093
No	144 (86.23)	152 (91.57)				
Patient reported that queues were too long (**Data for one patient was missing.)						
Yes	72 (43.37)	73 (43.71)	0.950	0.947	0.833	0.567 – 1.580
No	94 (56.29)	94 (56.29)				
Patient reported that staff do not treat patients with respect						
Yes	31 (18.56)	35 (20.96)	0.583	1.032	0.925	0.527 – 2.024
No	136 (81.44)	132 (79.04)				
Patient reported that facility was dirty (**Data for one patient was missing.)						
Yes	24 (14.37)	23 (13.86)	0.892	0.962	0.917	0.460 – 2.009
No	143 (85.63)	143 (86.14)				
Patient reported that they receive judgment from their community for attending the TB facility						
Yes	20 (11.98)	17 (10.18)	0.601	1.040	0.928	0.447 – 2.418
No	147 (88.02)	150 (89.82)				

^aControlling for: Education, Age, Sex, Province Born and Marital Status

^aControlling for: Education, Age, Sex, Province Born and Marital Status

[‡]Rounding may result in this column not summing to 100%

Table 4. Evaluation of Independent Effect of Socioeconomic Status on Various Parameters of Access by Logistic and Simple Regression Analysis

represents similar proportions of overall monthly health expenditure (3.00% and 1.00%, respectively) for both rich and poor groups. The direct costs of healthcare represent 13.00% of the total monthly household expenditure for poor patients and 7.00% for the rich.

With regards to perceptions of the acceptability of TB services, although none of the variables were found to be significantly associated with socioeconomic status, responses by the rich and the poor were marginally different for each of the variables included. Distinctly however, 13.77% of rich respondents reported that the staff members were too busy to

answer their questions, compared to only 8.43% of poor respondents.

Discussion

In interpreting the results, it is important to recognize the limitations of this study. The study uses a comprehensive framework of access to describe the barriers of access (and their effects on adherence) by users of free DOTS TB-services in Mitchell's Plain, South Africa. The study was based on the perspectives of users interviewed in five facilities within this setting. This analysis was limited to the sample of users and therefore, we cannot explore access barriers to DOTS TB-services which would contribute to the non-use of services. Second, where adherence has been evaluated, this analysis adopts a narrow definition of adherence, which relates only to missing doses of medication as reported by the patient. Correspondingly, given that this analysis was based on patient recall, there is the potential for both recall bias and social desirability bias whereby patients may either underreport missing doses of medication because they cannot recall doing so or because they believe it is more desirable to do so. Further, it is important to note that by using this definition of adherence, we are not implying that non-adherence amounts to treatment failure nor are we ignoring the fact that adherence can be governed by a range of variables in addition to medication adherence.

In earlier discussions, there is great emphasis on the importance of evaluating both health system and patient level forces which influence access to health services is stressed. This study only involves participation from patients therefore; the barriers to treatment access from the perspectives of health workers are not captured. In the absence of this data, there are a number of key barriers to treatment access which are not explored within the scope of this study.

The distance travelled to obtain TB treatment has been captured by the time taken to reach the health facility. Although this is a common means of doing so, it is important to understand that for many individuals, seeking treatment is combined with many other daily activities such as visiting friends and relatives or going to market. Thus, the time travelled to reach the facility may have been overestimated in some cases.

Finally, an important consideration when interpreting the findings of this study relate to those who were excluded from the sample of participants. The inclusion criteria mandated that only patients who had been receiving TB treatment for two months and who were deemed to be sufficiently well were able to be included in the sample, thus excluding those who withdrew from treatment, died, were lost-to-follow-up or were very ill, all of whom are likely to have been non-adherent.

By the definition of adherence employed within this study 73.05% met the criteria for adherence while 26.95% met the criteria for non-adherence. A recent systematic review of qualitative evidence regarding the determinants of TB medication adherence suggested that as many as half of all patients with TB will not complete treatment [28]. It may be possible that the level of non-adherence within this setting is in fact even lower than our result suggests. Although some have argued that any deviation or interruption in a prescribed TB-treatment regimen should be considered non-adherence [34], others have argued that because the exact effect of poor compliance with a prescribed TB-regimen is unknown, and that a certain degree of flexibility is unlikely to affect treatment outcome [27], [28], that patients should only be labeled as non-adherent if their level of non-adherence affects their therapeutic outcomes. Therefore, it becomes evident that adherence measures can be largely affected by the way in which the term is defined. Nonetheless, it is

important to consider that even if the methods of this study have potentially inflated the rate of non-adherence, rates of non-adherence to treatment are required to fall below 10% in order to achieve treatment success of 85%, one of the health-related indicators of the Millennium Development Goals [35].

According to our findings, a larger proportion of younger patients were found to be non-adherent. These results differ from similar studies in Nepal (2006) and Southern Ethiopia (2007) in which the former found a two-fold increase in non-adherence among patients over the age of fifty-four years and the latter found a significant association between being over the age of twenty-five years and treatment non-completion [36], [37]. A possible explanation for this result could be that older participants have a well-established network of social and community support, which is often a primary determinant of a household's ability to cope with the requirements of treatment [38]. In addition, older participants may have had more exposure to health-promotive interventions and may have a greater level of knowledge regarding treatment practices, the efficacy of treatment and the effects of poor-adherence. Furthermore, younger participants may be more likely to be vulnerable to ostracism and stigma associated with TB. As described in a number of studies TB patients will often miss appointments out of fear of being identified as a TB patient by their communities [28], [39], [40].

Marital status was also found to be significantly associated with adherence whereby a higher proportion of non-adherent participants were single than married. These findings are inconsistent with a similar study in Nepal (2006) which found significant differences in non-adherence between those that were single, married and widowed or divorced, where the likelihood of default increased when participants were married [36]. It is possible that within our setting, married respondents have a higher degree of support from their spouses which encourages and/or pressures them to adhere to the treatment regimen.

When we observed the association between the access variables and adherence, self-care costs and costs for other providers were the only variables which were found to be significantly associated with adherence. In both cases, adherent patients were seen to incur larger costs for these items. It could be the case that adherent patients are more likely to value their health and are therefore more likely to invest in over-the-counter medications, special foods and visits to other providers. When disaggregated by type, it is noteworthy that the largest proportion of healthcare costs are assumed by direct costs, which is largely composed of transport costs, consistent with other published studies [28], [29], [38]. For both adherent and non-adherent patients, direct costs represented 10% of total monthly household expenditure.

Although the association with adherence was not statistically significant, it is important to note that total healthcare costs were catastrophic for 32.21% of all respondents. Furthermore, costs were catastrophic for a larger proportion of poorer households compared to rich households, and on average, total costs represented a burden of 17.59% of the total household expenditure for poor households (Table 4). It is important to consider that the largest proportion of costs for TB-patients is assumed by the direct costs of seeking treatment, particularly those concerned with transportation (Figure 1). It has been widely accepted that where the total economic costs of illness represents 10% or more of a household's income, households are at risk of long-term impoverishment; although a lesser proportion is likely to be catastrophic for poorer households [41–43]. It is possible that many of these people will be unable to sustain these costs over the entire duration of treatment and may be forced to sacrifice vital resources to their household's livelihood such as food or education in order to cope with these costs [43].

Additional research is needed to explore the financial coping strategies employed by patients facing catastrophic healthcare costs in adhering to TB-treatment within this setting.

Another interesting finding reflected that more adherent patients felt that the staff did not treat patients with respect. Although this finding was not significantly associated with adherence, it talks to another element of TB-treatment. A number of studies have argued that the DOTS strategy is essential and is the most effective way of preventing relapse and the development of drug resistance; patients are able to be closely supervised and are coerced into adherence through peer pressure and other social influences [44]. However there are also a number of claims that the DOTS strategy is no more beneficial than self-supervised treatment; these critics also assert that directly observing treatment reverts to the former view of patients as passive recipients of treatment [44]. A number of studies have reflected how patients see direct-observation negatively and feel as though it indicates distrust between the provider and themselves [28]. In a South African trial which compared DOT to self-supervised treatment, direct-observation was seen to have a demoralizing effect on patients [44], [45]. In another study, directly-observed therapy was described as “humiliating, authoritarian and an invasion of privacy” [40] whereby approximately 45.00% of the patients reviewed reported that they were responsible enough to do so without observation and that they did not trust public services [40]. It is likely that the majority of adherent patients within this study interact more frequently with facility staff. It may be that the nature of direct-observation is the reason that many adherent patients feel a lack of respect from facility staff, although further study is required.

When the association between SES and each of the access variables were tested, there was no statistically significant evidence of inequalities in access by SES (all P-values > 0.05).

Both within South Africa and within other settings, it has been widely documented that the effects of TB have been particularly pronounced among poorer, disadvantaged groups who use health services less, despite their increased needs, and face increased barriers in accessing these services [25], [26]. As previously mentioned, the results reveal that the poor face increased costs of seeking treatment. Though these associations were not found to be significant, they warrant the attention of policy-makers.

The National Health Act (2003) explicitly focuses on the need to address “the socio-economic injustices, imbalances and inequities of health services of the past; the need to heal divisions of the past and to establish a society based on democratic values, social justice and fundamental human rights...” [12], [46]. This study reflects that despite the shortcomings of the South African health sector, the TB-service in Mitchell’s Plain appears to be distributed in a way that reflects the equity goals of the government. South Africa faces many challenges in successfully controlling the TB-epidemic over the next decade. We hope that our findings illustrate the potential of the TB-service, and the health system more widely, in reaching and treating all those in need.

Conclusion

Our findings indicate that non-adherence is not associated with access barriers and that there is no significant evidence to suggest that access barriers are higher for those of lower SES. These findings suggest that there is no evidence of systematic inequalities in access to DOTS TB-services in Mitchell’s Plain. However, this study elicits concerns about the high costs of using TB-services and the impact on households of catastrophic payments. This warrants a need to further explore the issue of transport costs – the main constituent of the direct monthly cost – which in turn is associated with the frequency of clinic visits.

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Conflicts of Interest: None

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PART D: POLICY BRIEF

ACCESS BARRIERS & TB-TREATMENT

EXPLORING EQUITY IN ACCESS TO TB-TREATMENT & THE INFLUENCE OF ACCESS BARRIERS ON TB-TREATMENT ADHERENCE IN MITCHELL'S PLAIN, SOUTH AFRICA

- NOT ADHERING TO TB TREATMENT IS NOT ASSOCIATED WITH ACCESS BARRIERS.
- THE DISTRIBUTION OF TB-SERVICES IN MITCHELL'S PLAIN, SOUTH AFRICA APPEARS TO BE EQUITABLE.
- THERE IS A NEED TO FURTHER EXPLORE THE HIGH COSTS OF USING TB-SERVICES.



Modified image taken from: (Nelson Mandela Bay Municipality 2012)

SOURCE

This policy brief is based on a journal article titled "An Analysis of Adherence & Equity in Access to TB-DOTS Services in Mitchell's Plain, South Africa"

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INTRODUCTION

South Africa faces one of the worst Tuberculosis (TB) epidemics in the world. Of every 100,000 South Africans, 904 are expected to develop TB. The national method of treating Tuberculosis, Directly Observed Treatment-Short Course (DOTS), has been supported by the World Health Organization (WHO) and is used globally to combat the disease. When a patient is treated using the DOTS strategy, they are typically required to take medication daily, over a period of six to eight months. The DOTS strategy requires that each patient be supervised; therefore, each patient is required to either: visit a health facility on a daily basis over the treatment period or be visited by a designated community-member who administers and supervises the patient consuming the medication. Despite the adoption of the DOTS strategy in 1996 and large financial investments in TB control, South Africa has not met the TB-related targets which have been set by the WHO. At current trends, 3.5 million people will develop TB and approximately 90,000 people will die as a result of the disease, over the next decade.

ACCESS BARRIERS & TB-TREATMENT

EXPLORING EQUITY IN ACCESS TO TB-TREATMENT & THE INFLUENCE OF ACCESS BARRIERS ON TB-TREATMENT ADHERENCE IN MITCHELL'S PLAIN, SOUTH AFRICA

Meeting the policy goal of identifying 70% of all new TB cases and successfully curing 85% of all TB patients enrolled in treatment in South Africa requires an understanding of the specific barriers being faced by those with TB, particularly in light of the availability of effective treatment. It is also important that access to TB-services is equitable i.e. distributed in a way that ensures that all in need have an equal opportunity to use TB services, regardless of social status, geographical location or other personal characteristics.

While TB services in the public sector are free at the point of use, little is known about overall access barriers and their implications for treatment adherence.

This brief summarizes these barriers from the perspective of TB patients enrolled in Directly Observed Treatment, Short-Course (DOTS) in Mitchell's Plain, South Africa.

RESEARCH OBJECTIVES

1. To describe the characteristics of adherent and non-adherent DOTS patients

Who is adhering and who isn't?

2. Explore the relationship between access to DOTS services and patient adherence

Do non-adherent patients face more access barriers than adherent patients?

3. Explore the relationship between access and socioeconomic status

Do the poor face more barriers to accessing DOTS services than the rich?

METHODS

During 2008 and 2009, exit interviews were conducted with 334 users of TB-services in Mitchell's Plain across five health facilities. Users were asked to report socioeconomic and demographic information as well as information regarding key barriers to DOTS TB-treatment accessibility. Users were deemed 'adherent' if they reported having never missed a dose of TB-medication and were deemed 'non-adherent' if they reported having missed one or more doses of TB-medication. In addition, users were grouped as 'rich' or 'poor' based on their socioeconomic status. Their experiences in accessing TB-services were compared by both adherence group and socioeconomic status using statistical software.

ACCESS BARRIERS & TB-TREATMENT

EXPLORING EQUITY IN ACCESS TO TB-TREATMENT & THE INFLUENCE OF ACCESS BARRIERS ON TB-TREATMENT ADHERENCE IN MITCHELL'S PLAIN, SOUTH AFRICA

KEY FINDINGS

- Among the respondents, 73% met the criteria for adherence while 27% met the criteria for non-adherence.
 - The median (interquartile range) age of the participants was 34 years (42-27) and 30 years (38-23.5) for the adherent and non-adherent groups.
- Age, Marital Status and the Province of the Respondent's birth were associated with adherence.
 - Users in older age groups were more likely to be adherent.
 - Users that were married were more likely to be adherent than those that were single.
 - Respondents who were born in the Eastern Cape Province were more likely to be adherent.

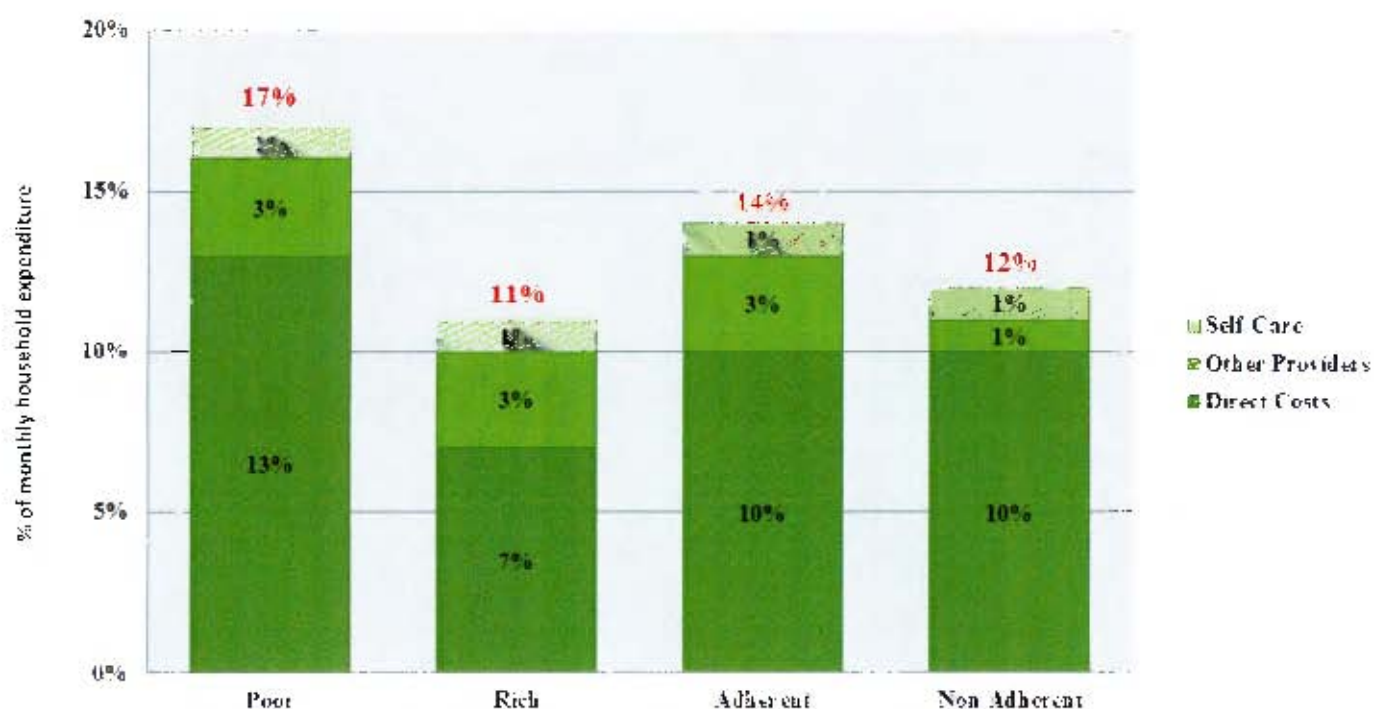
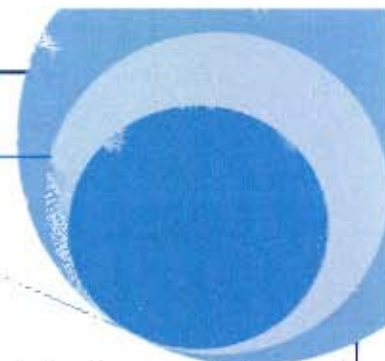


Figure 1
Expenditure on self care, direct costs and other providers as a percentage of household expenditure, by socioeconomic and adherence group.

ACCESS BARRIERS & TB-TREATMENT

EXPLORING EQUITY IN ACCESS TO TB-TREATMENT & THE INFLUENCE OF ACCESS BARRIERS ON TB-TREATMENT ADHERENCE IN MITCHELL'S PLAIN, SOUTH AFRICA



- Adherent patients incurred higher costs, but these costs were mainly incurred through using other providers (private general practitioners, traditional healers) and spending money on self care (special foods, traditional medicines, vitamins).
- Costs were catastrophic (i.e. represented over 10% of household expenditure) for 32% of respondents; of these users, a larger proportion were poor than rich. In total, the poor spent 17% of their household expenditure on TB-related care.
- Direct costs of transportation represented the largest burden of costs for all users.

Taken together, these findings do not provide sufficient evidence of systematic inequalities in access to DOTS TB-services in Mitchell's Plain, South Africa. Despite the fact that the poor were found to experience increased barriers to accessing treatment, by the high cost of seeking treatment, these associations were not found to be significant.

POLICY IMPLICATIONS

This study reflects that the TB-service in Mitchell's Plain appears to be distributed in a way that reflects the equity goals of the government. Nonetheless, this study elicits concerns about the high costs of using TB-services and the impact on households of catastrophic payments. This warrants a need to further explore the issue of transport costs – the main constituent of the direct monthly cost. South Africa faces many challenges in successfully controlling the TB-epidemic over the next decade. We hope that our findings illustrate the potential of the TB-service, and the health system more widely, in reaching and treating all those in need.

ACKNOWLEDGEMENTS

The findings presented in this policy brief were based on data collected as part of the REACH – Researching Equity in Access to Health Care – Project which was carried out with support from the Global Health Research Initiative, a collaborative research funding partnership of the Canadian Institutes of Health Research, the Canadian International Development Agency, Health Canada, the International Development Research Centre and the Public Health Agency of Canada. The funders had no involvement in study design or data collection. The authors are grateful to the REACH research team, particularly those who contributed to the methods development, data collection and study conceptualization. The authors would further like to acknowledge the patients and health workers who agreed to be involved in this project.

For a complete list of References, Please Contact the Author

APPENDIX A: EXIT INTERVIEW QUESTIONNAIRE

REACH

PATIENT EXIT INTERVIEW CONSENT FORM

TRACER: TB

CONSENT TO PARTICIPATE IN THE INTERVIEW

Facility: *[enter name of facility]* _____

**I HAVE BEEN INFORMED ABOUT THE PROJECT
RESEARCHING EQUITY IN ACCESS TO HEALTH CARE, AND I
UNDERSTAND THAT IT IS UP TO ME WHETHER OR NOT TO
BE INTERVIEWED.**

I understand that there will be no consequences of any kind through my responding to this questionnaire; in particular, there will be no impact on the care that I receive in this hospital.

I understand that I can ask the person interviewing me to stop the interview at any time.

I understand that the information that I give will be treated in the strictest confidence and that my name will not be used when the interviews are analysed.

Yes, I give my permission for the interview

☐

Interviewee's signature

Date

Interviewer's name (please print)

Interviewer's signature

Date

APPENDIX A: EXIT INTERVIEW QUESTIONNAIRE

SECTION 1: SOCIOECONOMIC AND DEMOGRAPHIC BACKGROUND QUESTIONS ABOUT THE RESPONDENT, HIS/HER HOUSEHOLD AND HOUSEHOLD HEAD

READ OUT:

I am going to start by asking you a few questions about you and your household. When I talk about your household, I am including all the people who live in your house and who share the same food with you.

When I talk about your household head, this is the person who usually makes the important decisions in the household.

1.1		Male	1
Sex		Female	2
1.2		African/Black	1
Note the race of the respondent. If you are not certain, ask: How would you describe yourself racially?		Coloured	2
		Asian/Indian	3
		White	4
		Other	97
		If other, specify	
1.3			
What was your age at your last birthday?			
Fill in one block only		Year born	Years
1.4			
Who is the head of your household? By this, I mean, who is the person who usually makes the important decisions in the household. Indicate relationship e.g. father, mother not name.		Relationship	
1.5		Male	1
Code sex of HHH. If not clear ask: What is the sex of your HHH?		Female	2
1.6		Head/acting head	1
Code position in HH of respondent. If unclear, ask:		Husband/wife/partner	2
What is your position in the household, in relation to the household head such as ... read out a few relevant options.		Son/daughter/stepchild/adopted child	3
Circle one only		Brother/sister/step brother/step sister	4
		Father/mother/step father/step mother	5
		Grandparent/great grandparent	6
		Grandchild/great grandchild	7
		Other relative (e.g. in laws or aunt/uncle)	8
		Non-related persons (tenant, boarder, lodger)	9
		Don't know	99
		Other	97
		If other, specify	
1.7			
What was the age of your HHH i.e. husband / father / mother etc. at his/her last birthday? Fill in one block only		Year born	Years
1.8		Yes	1
Does your HHH i.e. husband / father / mother etc. stay with you for at least 2 weeks each month?		No	0

If respondent HHH, go to 1.9

APPENDIX A: EXIT INTERVIEW QUESTIONNAIRE

1.14 Including yourself, how many adults (18 years or older) live in your household? When I talk about your household, I am including all the people who live in your house and who share the same food with you.		No. Adults 18 or older	
1.15 How many children (younger than 18 years) live in your household?		No. Children under 18	
1.16 Does anyone in your household receive a government grant OR income from the government such as ... read out each option and circle yes or no on every row. If YES ask: How many of each type of grant is received (i.e. how many people receive each?)	Type of grant	Yes	No
	Unemployment Insurance (UIF)	1	0
	Worker's compensation	1	0
	State old age pension	1	0
	Disability grant	1	0
	Child support grant	1	0
	Care dependency grant	1	0
	Foster care grant	1	0
	Grant in aid	1	0
	Social relief	1	0
Other	1	0	
Don't know	99		
1.17 If someone in the household receives a disability grant, ask Is it you that receives the disability grant?		Yes	No
1.18 If YES ask What is the reason that you receive this disability grant?		1 0	
1.19 If NO ask Have you applied for a disability grant?		Yes	No
1.20 Where were you born? READ OUT I know this is a sensitive question to ask at this stage, but we are asking because we want to see if health services treat South Africans differently to those who are not from South Africa.		South Africa Other If other, specify	
1.21 If respondent born in South Africa, ask: Which province were you born in? Use current province borders		Western Cape Eastern Cape Northern Cape Free State KwaZulu-Natal North West Gauteng Mpumalanga Limpopo Don't Know	

APPENDIX A: EXIT INTERVIEW QUESTIONNAIRE

READ OUT: Some people find it quite hard to stick to their TB treatment and might not always be able to make their appointments at the clinic. We are now going to ask you about whether you have had any of these sorts of problems and what the reasons might be.

2.10 Did you miss taking any of your TB tablets YESTERDAY?	Yes	1
	No	0
2.11 Did you miss taking any TB tablets the day before YESTERDAY?	Yes	1
	No	0
2.12 Did you miss taking any TB tablets 3 DAYS AGO? Specify the calendar day in relation to the day of the interview	Yes	1
	No	0
2.13 Apart from the last three days, have you ever missed taking any tablets?	Yes	1
	No	0

2.14 Have you missed any of the following since you started TB treatment for this current episode	Type of visit	Yes	No	N/A	If YES, how many?
	Daily DOTS visit	1	0	98	
	Nurse/doctor clinic visit	1	0	98	
	TB treatment collection	1	0	98	

If all no or N/A go to 2.16

2.15 For the last appointment missed, what was your reason(s)? Do not read the list aloud; prompt respondent to give you up to three reasons. Circle up to three yes options and circle all others no	Reason	Yes	No
	Lack of money	1	0
	Lack of time	1	0
	I felt better	1	0
	I could not take time off from work	1	0
	No transport	1	0
	Too ill to travel	1	0
	Other responsibilities	1	0
	The treatment is not effective / does not make me feel better	1	0
	The queues in the facility are too long	1	0
	The staff are rude or uncaring	1	0
	I have had bad experiences with staff in the past	1	0
	Don't know	99	
	Other	97	
	Other 1 (specify)		
	Other 2 (specify)		

APPENDIX A: EXIT INTERVIEW QUESTIONNAIRE

3.6 What would you have been doing if you weren't at the clinic today? Circle "Yes" or "No" on every row.	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left;">Activity</th> <th style="text-align: center;">Yes</th> <th style="text-align: center;">No</th> </tr> </thead> <tbody> <tr> <td>Working for pay</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Doing unpaid community work or volunteer work</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Doing household chores such as cleaning, cooking, shopping for food, maintenance and repairs, working in the garden, gathering wood, gathering water, housework etc.</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Taking care of children</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Leisure activities (sport, watching TV, listening to music, reading, visiting friends and family, going to movies etc)</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Attending school or other educational institution</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Nothing</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>I don't know</td> <td colspan="2" style="text-align: center;">99</td> </tr> <tr> <td>Other</td> <td colspan="2" style="text-align: center;">97</td> </tr> <tr> <td colspan="3">If other, specify</td> </tr> </tbody> </table>	Activity	Yes	No	Working for pay	1	0	Doing unpaid community work or volunteer work	1	0	Doing household chores such as cleaning, cooking, shopping for food, maintenance and repairs, working in the garden, gathering wood, gathering water, housework etc.	1	0	Taking care of children	1	0	Leisure activities (sport, watching TV, listening to music, reading, visiting friends and family, going to movies etc)	1	0	Attending school or other educational institution	1	0	Nothing	1	0	I don't know	99		Other	97		If other, specify			
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I don't know	99																																		
Other	97																																		
If other, specify																																			
3.7 In coming to receive treatment today, how much did you pay for Read out each item. If no money spent, code as "0" for each item	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left;">Category</th> <th style="text-align: center;">Rand</th> </tr> </thead> <tbody> <tr> <td>Transport (one way)</td> <td></td> </tr> <tr> <td>Clinic fees</td> <td></td> </tr> <tr> <td>Medicines</td> <td></td> </tr> <tr> <td>Someone to take over your tasks while you are here including childcare</td> <td></td> </tr> <tr> <td>Accommodation if you need to stay the night nearby</td> <td></td> </tr> <tr> <td>Food during visit</td> <td></td> </tr> <tr> <td>Phoning or sms'ing</td> <td></td> </tr> <tr> <td>Other, specify:</td> <td></td> </tr> </tbody> </table>	Category	Rand	Transport (one way)		Clinic fees		Medicines		Someone to take over your tasks while you are here including childcare		Accommodation if you need to stay the night nearby		Food during visit		Phoning or sms'ing		Other, specify:		<div style="border: 1px solid black; padding: 5px; transform: rotate(-90deg); transform-origin: center;"> If no expense, go to 3.9 </div>															
Category	Rand																																		
Transport (one way)																																			
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Someone to take over your tasks while you are here including childcare																																			
Accommodation if you need to stay the night nearby																																			
Food during visit																																			
Phoning or sms'ing																																			
Other, specify:																																			
3.8 Did you find it easy or difficult to incur these expenses? Refer to expenses in 3.7	<table border="1" style="width: 100%; border-collapse: collapse;"> <tbody> <tr> <td style="text-align: left;">Easy</td> <td style="text-align: center;">1</td> </tr> <tr> <td style="text-align: left;">Difficult</td> <td style="text-align: center;">2</td> </tr> <tr> <td style="text-align: left;">Neither easy nor difficult</td> <td style="text-align: center;">3</td> </tr> <tr> <td style="text-align: left;">Don't know</td> <td style="text-align: center;">99</td> </tr> </tbody> </table>	Easy	1	Difficult	2	Neither easy nor difficult	3	Don't know	99																										
Easy	1																																		
Difficult	2																																		
Neither easy nor difficult	3																																		
Don't know	99																																		
3.9 If respondent is working Did you lose money from the time you took from your job to come here today?	<table border="1" style="width: 100%; border-collapse: collapse;"> <tbody> <tr> <td style="text-align: left;">Yes</td> <td style="text-align: center;">1</td> </tr> <tr> <td style="text-align: left;">No</td> <td style="text-align: center;">0</td> </tr> </tbody> </table>	Yes	1	No	0	<div style="border: 1px solid black; padding: 5px; transform: rotate(-90deg); transform-origin: center;"> If no go to 3.11 </div>																													
Yes	1																																		
No	0																																		
3.10 If YES: How much money did you lose?	<div style="border: 1px solid black; padding: 5px; text-align: center;"> (Rand) </div>																																		
3.11 Who has been helping you financially, i.e. with cash, buying food, providing transport etc, with your TB? Circle "Yes" or "No" on every row	<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left;">Person</th> <th style="text-align: center;">Yes</th> <th style="text-align: center;">No</th> </tr> </thead> <tbody> <tr> <td>Husband/wife</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Father/mother</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Boyfriend/girlfriend</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Other relatives</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Friends</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Nobody</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Employer (over and above normal wages)</td> <td style="text-align: center;">1</td> <td style="text-align: center;">0</td> </tr> <tr> <td>Don't know</td> <td colspan="2" style="text-align: center;">99</td> </tr> <tr> <td>Other</td> <td colspan="2" style="text-align: center;">97</td> </tr> </tbody> </table>	Person	Yes	No	Husband/wife	1	0	Father/mother	1	0	Boyfriend/girlfriend	1	0	Other relatives	1	0	Friends	1	0	Nobody	1	0	Employer (over and above normal wages)	1	0	Don't know	99		Other	97					
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Other	97																																		

APPENDIX A: EXIT INTERVIEW QUESTIONNAIRE

READ OUT: For the following three questions, please tell me whether you agree or disagree with the statements I make.

5.3 "I have all the support from my partner that I need to cope with my illness?"	Agree	1
	Disagree	0
	Don't know	99
	Not applicable	98
5.4 "I have all the support that I need from my family"	Agree	1
	Disagree	0
	Don't know	99
	Not applicable	98
5.5 "I have all the support that I need from my friends"	Agree	1
	Disagree	0
	Don't know	99
	Not applicable	98
5.6 Do you feel that people in the community judge you negatively for attending this facility for your TB treatment?	Yes	1
	No	0
	Don't know	99
5.7 In general, when you need to seek healthcare, what do you prefer: a) To see a nurse in a nearby clinic or b) To travel further to see a doctor	Nurse	1
	Doctor	2
	Indifferent	3
	Don't know	99
5.8 In this clinic are you able to talk to the doctors or nurses in private?	Always	1
	Sometimes	2
	Never	3

READ OUT: Can you tell me whether you agree or disagree with these statements when thinking about your general experience in this clinic?

5.9 The queues to see a doctor or nurse are too long at this facility	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.10 The doctors and nurses (<i>health workers</i>) discussed the treatment fully with me	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.11 It is a problem that the <i>health workers</i> DO NOT speak my language	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99
5.12 I find it easy to tell the <i>health workers</i> when I have missed taking my tablets	Agree	1
	Disagree	0
	Both agree and disagree	2
	Don't know / not sure	99

APPENDIX A: EXIT INTERVIEW QUESTIONNAIRE

5.23 How do you think the service in this clinic could be improved? Circle 'Yes' or 'No' on every row.	Improvement	Yes	No
	Shorter queues	1	0
	More health workers	1	0
	Cleaner facilities	1	0
	Better patient facilities (toilets, waiting room area etc)	1	0
	Don't know	99	
	Other	97	
If other, specify			

SECTION 6: DWELLING CHARACTERISTICS, HOUSEHOLD INCOME, EXPENDITURE AND HOUSEHOLD ASSETS			
READ OUT: Finally, we want to ask you some questions about the characteristics of the house where you live and type of facilities available within your household			

6.1 Where do you live?	_____ village of community _____ area of township		
----------------------------------	--	--	--

6.2 Which best describes the type of house in which you live? Clarify answer Circle one only	House or brick structure on a separate stand or yard or on farm	1
	Traditional dwelling/hut/structure made of traditional materials	2
	Flat	3
	Town/cluster/semi-detached house (simplex, duplex or triplex)	4
	Unit in retirement village	5
	Dwelling/house/flat/room in backyard	6
	Informal dwelling/shack IN the backyard of a formal house	7
	Informal dwelling/shack NOT in backyard e.g. in an informal/squatter settlement or on farm	8
	Room/flatlet not in backyard but on a shared property e.g. granny flat	9
	Caravan/tent	10
	Worker's hostel	11
	Other	97
	If other, specify	

6.3 What is the main material of your house's walls? Clarify answer Circle one only	Bricks & plaster/finished	1
	Bare brick/cement block	2
	Corrugated iron/zinc	3
	Wood	4
	Plastic	5
	Cardboard	6
	Mixture of mud and cement	7
	Wattle and daub	8
	Mud	9
	Other	97

APPENDIX A: EXIT INTERVIEW QUESTIONNAIRE

6.4 What is the main material of your house's roof? Clarify answer Circle one only	Tiles	1
	Corrugated iron/zinc	2
	Thatching	3
	Asbestos	4
	Plastic	5
	Cardboard	6
	Other	97
	If other, specify	
6.5 How many rooms, including kitchens, does your house have? Interviewer, probe and exclude bathrooms, sheds, garages, stables, etc. from the total unless people are living in them <div style="text-align: right;">_____ No. rooms</div>		
6.6 What is the main source of drinking water for members of your household? Clarify answer Circle one only	Piped (tap) water in dwelling	1
	Piped (tap) water on site or in yard	2
	Borehole on site	3
	Rain water tank on site	4
	Neighbour's tap	5
	Public/communal tap (either free or paid)	6
	Water carrier/tanker	7
	Borehole off site/communal	8
	Flowing water/stream/river	9
	Stagnant water/dam/pool	10
	Well	11
	Spring	12
	Other	97
	If other, specify	
6.7 What type of toilet does your household use? Clarify answer Circle one only	Flush toilet (connected to sewage)	1
	Flush toilet (with septic tank)	2
	Chemical toilet	3
	Pit latrine with ventilation pipe	4
	Pit latrine without ventilation pipe	5
	Bucket toilet	6
	No facility/bush/field	7
	Other	97
	If other, specify	

APPENDIX A: EXIT INTERVIEW QUESTIONNAIRE

6.10 Does your household own cattle, livestock or chickens?	Yes No	1 0	If no go to 6.16
6.11 IF YES			
How many cattle does the household own?	(No. cattle)		
	None	0	
	Don't know	99	
6.12 IF YES			
How many goats does the household own?	(No. goats)		
	None	0	
	Don't know	99	
6.13 IF YES			
How many chickens does the household own?	(No. chickens)		
	None	0	
	Don't know	99	
6.14 IF YES			
How many pigs does the household own?	(No. pigs)		
	None	0	
	Don't know	99	
6.15 IF YES	If other, specify		
Does the HH own any other farm animals? IF YES What are they			
How many [other] does the household own?	(No. other)		
	None	0	
	Don't know	99	

APPENDIX B: RECORD REVIEW QUESTIONNAIRE

RESEARCHING EQUITY IN ACCESS TO HEALTH CARE RECORD REVIEW OF TUBERCULOSIS SERVICES: CONSENT FORM

Facility: *[enter name of facility]* _____

I have been informed about the project *Researching equity in access to health care*, and I understand that it is up to me whether or not to allow my medical record to be reviewed.

I understand that there will be no consequences of any kind through my agreement to this request; in particular, there will be no impact on the care that I receive in this clinic/hospital.

I understand that the information obtained from my patient medical record will be treated in the strictest confidence and that my name will not be used when the information is analysed.

Yes, I give my permission to review my record

☐

Interviewee's signature

Date

Interviewer's name (please print)

Interviewer's signature:

Date

APPENDIX B: RECORD REVIEW QUESTIONNAIRE

Record Review

INSTRUCTIONS

- Make sure that the patient's study sticker is attached below.
- Complete the information overleaf using the patient's blue card.
- The completed questionnaire must be attached to the patient's exit interview.
- Once quality control has been completed the front page will be detached and kept separately. This part of the questionnaire must remain with the completed exit interview.

Study sticker:

--

Completed by:

--

Date completed:

d	d		m	m		y	y	y	y
		/			/				

Blue card found?

Yes	No
-----	----

Quality checked by:

--

APPENDIX B: RECORD REVIEW QUESTIONNAIRE

A. RECORDING & REPORTING

The section is concerned with the general level of **completeness** of the blue card, that is whether or not all the required information has been filled in. Circle **Yes** or **No** to indicate if the following information is filled in on the card. Only circle **Yes** if ALL the required information is completed. Circle **No** if there is no information filled in or the information is incomplete or the information is not available on your version of the card.

Page 1 :

1. Registration number	Yes	No
2. Registration date	Yes	No
3. Patient origin (N, M or T ticked in upper right hand corner)	Yes	No
4. Full names of patient	Yes	No
5. Patient ID number	Yes	No
6. Patient date of birth	Yes	No
7. Patient age	Yes	No
8. Patient gender	Yes	No
9. Patient home and work addresses	Yes	No
10. Address in sufficient detail to trace patient (Clear description if no formal address)	Yes	No
11. Name and addresses of next of kin	Yes	No
12. Patient category	Yes	No
13. Disease classification	Yes	No
14. Notification date	Yes	No

Page 2 :

15. Pre-treatment sputum results	Yes	No
16. Intensive phase regimen and dosage	Yes	No
17. Continuation phase regimen and dosage	Yes	No
18. Adherence section up to date (To 1 week ago if weekly Rx / To 1 month ago if monthly Rx)	Yes	No
19. Name and contact details of treatment supervisor (For both phases on new form)	Yes	No

Page 3 :

20. HIV status	Yes	No
21. Clinical notes on patient progress	Yes	No
22. Patient's weight recorded at each visit	Yes	No

Page 4 :

23. Patient contact section filled in (No Contacts should be written if there were no contacts)	Yes	No
24. Treatment outcome recorded	Yes	No
25. Discharge date recorded for patients that completed treatment	Yes	No

APPENDIX B: RECORD REVIEW QUESTIONNAIRE

B. CLINICAL MANAGEMENT

The section is concerned with whether or not the completed information is **correct** and the patient has been managed **correctly**. For each question below simply copy the required information directly from the card. Note that not all answers may be appropriate or completed for your patient. If the information is not available please write **N/A** in the box or next to the question.

1. Version of the card (Date in top right corner Eg: Sep 2002 or Nov 2006)

--

2. Patient's registration date

d	d			/	m	m			/	y	y	y	y

3. Patient's birth date

d	d			/	m	m			/	y	y	y	y

4. Patient category

N	RC	RAC	RF	RD	OR
---	----	-----	----	----	----

5. Classification of disease

Pulmonary TB	TB Primary	Extra PTB / Any other TB
--------------	------------	-----------------------------

6. Patient has been notified? (Y ticked AND date recorded)

Yes	No
-----	----

7. Record all the **sputum** test dates and results listed for the patient on the form:

		Smear Date									Smear Result	
		d	d		m	m		y	y	y	y	
Pre-Treatment	i.			/			/					
	ii.			/			/					
End of intensive phase	i.			/			/					
	ii.			/			/					
	iii.			/			/					
	iv.			/			/					
Discharge / End of treatment	i.			/			/					
	ii.			/			/					

8. Record all the **culture** test dates and results listed for the patient on the form:

	Culture Date									Culture Result	
	d	d		m	m		y	y	y	y	
i.			/			/					
ii.			/			/					

APPENDIX B: RECORD REVIEW QUESTIONNAIRE

9. Drug Regimen

1	2	3
---	---	---

10. Treatment start date

d	d		m	m		y	y	y	y
<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	/	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	/	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>

11. Patient's weight at diagnosis

kg

12. Drug dosage in **INTENSIVE** phase

	RHZE	RHZ	S	E
Number of tablets / dose	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>

13. Drug dosage in **CONTINUATION** phase

	RH (150/75)	RH (300/150)	RH (60/30)	E
Number of tablets / dose	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>

14. Number of visits missed. (Count the total number of Xs in calendar section on page 2 for each phase)

Intensive phase	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>
Continuation phase	<div style="border: 1px solid black; width: 100%; height: 20px;"></div>

15. Any patient contacts?

Yes	No
-----	----

If **YES**, check contact tracing done correctly?

All children (< 5 years) had X-Ray AND Mantoux/tuberculin test

All adults (> 13 years) had sputum test

Yes	No
Yes	No

16. Treatment outcome

Not Recorded	
Patient transferred / Moved	
Cured	
Treatment completed	
Treatment defaulted / interrupted	
Treatment failure	
Died	

17. Treatment outcome date

d	d		m	m		y	y	y	y
<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	/	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	/	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>	<div style="border: 1px solid black; width: 20px; height: 20px;"></div>

APPENDIX C: ETHICS CLEARANCE

UNIVERSITY OF CAPE TOWN



Health Sciences Faculty
Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone (021) 406 6335 • Facsimile (021) 406 6417
e-mail: research@ethics.uct.ac.za

07 November 2007

REC REF: 460/2006

A/Prof D McIntyre
Health Economics Unit
School of Public Health

Dear A/Prof McIntyre

PROJECT TITLE: RESEARCHING EQUITY IN ACCESS TO HEALTH CARE (REACH)

Thank you for your letter to the Research Ethics Committee dated 26th October 2007.

It is a pleasure to inform you that the Ethics Committee has **granted ethical approval** to use the set of data gathering tools and information sheets and informed consent forms described in appendices 1-18.

Please could you address the following two concerns:

- Will patient-participants receive any compensation for taking part in the in-depth interviews (semi-structured and narratives)? These are long and may be burdensome for some patients.
- Do you intend to take any action should you observe harmful staff-patient interaction? You indicate that all observations will be strictly confidential which might pose an ethical dilemma should 'patient-abuse' be observed by researchers.

Please would you notify Dr Tracey Naledi in the Western Cape Department of Health that you are undertaking this study. You indicate that you already have provincial permission to do this research, so it may be a redundant exercise (I'll email you her latest requirements).

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC REF in all your correspondence.

Yours sincerely

PROF M BLOCKMAN
CHAIRPERSON, UCT HUMAN ETHICS

Enclosed

APPENDIX D: JOURNAL INSTRUCTIONS FOR AUTHORS

JOURNAL HEALTH POLICY

Size and Layout

Manuscripts should be written in English. They should be clear, concise and logical.

Manuscripts should be structured as follows:

- Title Page
- Abstract
- Introduction
- Materials and methods
- Results
- Discussion
- Conclusions
- Acknowledgements (e.g. to sponsors)
- Conflicts of interest
- References

TITLE PAGE

- **Title**
Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
- **Author names and affiliations**
Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address.
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Authors are asked to classify their submission using the provided classification system. They are also asked to include 3 to 6 keywords, preferably from the Medical Subject Headings from *Index Medicus*.

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An abstract of up to 200 words must be included in the submitted manuscript. As the abstract is often viewed separately from the article, it must be able to stand alone. It should state briefly and clearly the purpose and setting, the principal findings and major conclusions, and the paper's contribution to knowledge. If applicable, the country/countries/locations should be clearly stated, as should the methods and nature of the sample, the dates, and a summary of the findings/conclusion.

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Figures and tables, and especially equations or other formulae should be kept to a minimum. Only those figures, tables and equations that are essential to clarify arguments in the manuscript should be included. Except in exceptional circumstances, the admissible number of figures and tables together is 2 for short articles, 4 for full-length articles and 6 for review-type articles. Additional figures and tables may be supplied as supplementary data

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Citation of literature references in the text should be done as numbers in square brackets. All references should be listed at the end of the paper on a separate page, arranged in numerical order of their appearance in the text, not in alphabetical order.

The Authors should ensure that there is a strict one-to-one correspondence between the names and years in the text and those on the reference list.

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All authors are requested to disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work.

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You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. If the funding source(s) had no such involvement then this should be stated.

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PLAGIARISM DECLARATION

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Date

30 OCTOBER-2012

Signature

APPENDIX F: ACKNOWLEDGEMENTS

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